2021 Compendium of Disability Data Collection Methods

January 31, 2021

Jason Markesich, Stacie Feldman, & William Rafferty

Submitted to:

University of New Hampshire, Institute on Disability
51 College Road
Durham, NH 03824
Project Officer: Andrew Houtenville
Contract No. P19UFZ59

Submitted by:

Mathematica
Center for Studying Disability Policy
600 Alexander Park
Princeton, NJ 08540
Project Director: David Mann
Mathematica Reference No. 51133.Y3.DM4.000.000

CONTENTS

This page has been left blank for double sided copying.

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 2021 version of the compendium, an indexed reference list, contains 441 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)

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 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.

E-mail: JMarkesich@mathematica-mpr.com

SFeldman@mathematica-mpr.com

Info@mathematica-mpr.com

CHAPTER II. LISTING BY SUBJECT

A. Disability/Impairment Type

1. Aging and Later-Life Disabilities

Alvarez-Nebreda, M. Loreto, Marilyn Heng, Bernard Rosner, Michael McTague, Houman Javedan, Mitchel B. Harris, and Michael J. Weaver. "Reliability of Proxy-Reported Patient-Reported Outcomes Measurement Information System Physical Function and Pain Interference Responses for Elderly Patients with Musculoskeletal Injury" *The Journal of the American Academy of Orthopaedic Surgeons,* vol. 27, no. 4, 2019, pp. e156–e165.

Baker, Ashleigh T., Julie E. Byles, Deborah J. Loxton, Deirdre McLaughlin, Anna Graves, and Annette Dobson. "Utility and Acceptability of the Modified Telephone Interview for Cognitive Status in a Longitudinal Study of Australian Women Aged 85 to 90." *Journal of the American Geriatrics Society,* vol. 61, no. 7, 2013, pp. 1217–1220.

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.

Bentvelzen, Adam C., John D. Crawford, Adam Theobald, Kate Maston, Melissa J. Slavin, Simone Reppermund, Kristan Kang, Katya Numbers, Henry Brodaty, Perminder Sachdev, et al. "Validation and Normative Data for the Modified Telephone Interview for Cognitive Status: The Sydney Memory and Ageinggar Study." *Journal of the American Geriatrics Society,* vol. 67, no. 10, 2019, pp. 2108–2115.

Beullens, Koen, Geert Loosveldt, and Caroline Vandenplas. "Interviewer Effects Among Older Respondents in the European Social Survey." *International Journal of Public Opinion Research,* vol. 31, no. 4, 2019, pp. 609–625.

Bode, Liv, and Christa Scheidt-Nave. "European and Global Approaches to Survey Ageing Populations and Perspectives for Joint Approaches to Measure Age-Related Health Outcomes." *BMC Proceedings,* vol. 7, suppl. 4, 2013, online only.

Bousquet, Jean, Joao Malva, Michel Nogues, Leocadio R. Mañas, Bruno Vellas, and John Farrell. "Operational Definition of Active and Healthy Aging (AHA): The European Innovation Partnership (EIP) on AHA Reference Site Questionnaire: Montpellier October 20–21, 2014, Lisbon July 2, 2015." *Journal of the American Medical Directors Association,* vol. 16, no. 12, 2015, pp. 1020–1026.

Brehmer-Rinderer, Barbara, Elisabeth L. Zeilinger, Ana Radaljevic, and Germain Weber. "The Vienna Frailty Questionnaire for Persons with Intellectual Disabilities—Revised." *Research in Developmental Disabilities,* vol. 34, no. 6, 2013, pp. 1958–1965.

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.

Carvalho, Janessa O., Beth Springate, Rachel A. Bernier, and Jennifer Davis. "Psychometrics of the AAN Caregiver Driving Safety Questionnaire and Contributors to Caregiver Concern About Driving Safety in Older Adults." *International Psychogeriatrics,* vol. 30, no. 3, 2018, pp. 355–364.

Chen, Hsin-Hao, Fang-Ju Sun, Tzu-Lin Yeh, Hsueh-Erh Liu, Hsiu-Li Huang, Benjamin I. Kuo, and Hsin-Yi Huang. "The Diagnostic Accuracy of the Ascertain Dementia 8 Questionnaire for Detecting Cognitive Impairment in Primary Care in the Community, Clinics and Hospitals: A Systematic Review and Meta-Analysis." *Family Practice,* vol. 35, no. 3, 2018, pp. 239–246.

Cridland, Elizabeth K., Lyn Phillipson, Christopher Brennan-Horley, and Kate Swaffer. "Reflections and Recommendations for Conducting In-Depth Interviews with People with Dementia." *Qualitative Health Research,* vol. 26, no. 13, 2016, pp. 1774–1786.

Davis, Jennifer C., Ging-Yuek Hsiung, Stirling Bryan, Claudia Jacova, Patrizio Jacova, Michelle Munkacsy, Winnie Cheung, Philip Lee, and Teresa Liu-Ambrose. "Agreement Between Patient and Proxy Assessments of Quality of Life Among Older Adults with Vascular Cognitive Impairment Using the EQ-5D-3L and ICECAP-O." *PLoS ONE,* vol. 11, no. 4, 2016, online only.

de Vries, Kay, Carol J. Leppa, Rosemarie Sandford, and Vasso Vydelingum. "Administering Questionnaires to Older People: Rigid Adherence to Protocol May Deny and Disacknowledge Emotional Expression." *Journal of Aging Studies,* vol. 31, 2014, pp. 132–138.

Di Bari, Mauro, Francesco Profili, Stefania Bandinelli, Anna Salvioni, Enrico Mossello, Carla Corridori, Matilde Razzanelli, Teresa Di Fiandra, and Paolo Francesconi. "Screening for Frailty in Older Adults Using a Postal Questionnaire: Rationale, Methods, and Instruments Validation of the INTER-FRAIL Study." *Journal of the American Geriatrics Society,* vol. 62, no. 10, 2014, pp. 1933–1937.

Digby, Robin, Susan Lee, and Allison Williams. "Interviewing People with Dementia in Hospital: Recommendations for Researchers." *Journal of Clinical Nursing,* vol. 25, no. 7-8, 2016, pp. 1156–1165.

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.

Gaertner, Beate, Ina Seitz, Judith Fuchs, Markus A. Busch, Martin Holzhausen, Peter Martus, and Christa Scheidt-Nave. "Baseline Participation in a Health Examination Survey of the Population 65 Years and Older: Who Is Missed and Why?" *BMC Geriatrics,* vol. 16, no. 21, 2016, online only.

Gardner, Raquel C., Ernesto Rivera, Megan O'Grady, Colin Doherty, Kristine Yaffe, John D. Corrigan, Jennifer Bogner, Joel Kramer, Fiona Wilson, Rudy Castellani, et al. "Screening for Lifetime History of Traumatic Brain Injury Among Older American and Irish Adults at Risk for Dementia: Development and Validation of a Web-Based Survey." *Journal of Alzheimer's Disease,* vol. 74, no. 2, 2020, pp. 699–711.

Gregersen, Merete, Mette M. Jordansen, and Debby L. Gerritsen. "Overall Quality of Life (OQoL) Questionnaire in Frail Elderly: A Study of Reproducibility and Responsiveness of the Depression List (DL)." *Archives of Gerontology and Geriatrics,* vol. 60, no. 1, 2015, pp. 22–27.

Gruters, Angélique A.A., Inez H.G.B. Ramakers, Frans R.J. Verhey, Sebastian Köhler, Roy P.C. Kessels, Marjolein E. de Vugt, and Katherine Gifford. "Association Between Proxy- or Self-Reported Cognitive Decline and Cognitive Performance in Memory Clinic Visitors." *Journal of Alzheimer's Disease,* vol. 70, no. 4, 2019, pp. 1225–1239.

Hendriks, A.A. Jolijn, Sarah C. Smith, Theopisti Chrysanthaki, and Nick Black. "Reliability and Validity of a Self-Administration Version of DEMQOL-Proxy." *International Journal of Geriatric Psychiatry*, vol. 32, no. 7, 2017, pp. 734–741.

Jakobsson, Elin, Louise Nygård, Anders Kottorp, Cecilia B. Olsson, and Camilla Malinowsky. "The Use of Everyday Technology: A Comparison of Older Persons with Cognitive Impairments' Self-Reports and their Proxies' Reports." *British Journal of Occupational Therapy,* 2020.

Kelfve, Susanne, Mats Thorslund, and Carin Lennartsson. "Sampling and Non-Response Bias on Health-Outcomes in Surveys of the Oldest Old." *European Journal of Ageing,* vol. 10, no. 3, 2013, pp. 237–245.

Kelfve, Susanne. "Underestimated Health Inequalities Among Older People—A Consequence of Excluding the Most Disabled and Disadvantaged." *Journals of Gerontology Series B,* vol. 74, no. 8, 2019, pp. e125–e134.

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.

Koolhaas, Chantal M., Frank J. van Rooij, Magda Cepeda, Henning Tiemeier, Oscar H. Franco, and Josje D. Schoufour. "Physical Activity Derived from Questionnaires and Wrist-Worn Accelerometers: Comparability and the Role of Demographic, Lifestyle, and Health Factors Among a Population-Based Sample of Older Adults." *Clinical Epidemiology,* vol. 10, 2017, pp. 1–16.

Kotwal, Ashwin A., Philip Schumm, David W. Kern, Martha K. McClintock, Linda J. Waite, Joseph W. Shega, Megan J. Huisingh-Scheetz, and William Dale. "Evaluation of a Brief Survey Instrument for Assessing Subtle Differences in Cognitive Function Among Older Adults." *Alzheimer Disease and Associated Disorders,* vol. 29, no. 4, 2015, pp. 317–324.

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.

Lindgren, Noora, Juha O. Rinne, Teemu Palviainen, Jaakko Kaprio, and Eero Vuoksimaa. "Prevalence and Correlates of Dementia and Mild Cognitive Impairment Classified with Different Versions of the Modified Telephone Interview for Cognitive Status (TICS–m)." *International Journal of Geriatric Psychiatry,* vol. 34, no. 12, 2019, pp. 1883–1891.

Lutomski, Jennifer E., Maria A.E. Baars, Janneke A. van Kempen, Bianca M. Buurman, Wendy P.J. den Elzen, Aaltje P.D. Jansen, Gertrudis I.J.M. Kempen, Paul F.M. Krabbe, Bas Steunenberg, Ewout W. Steyerberg, Marcel G.M. Olde-Rikkert, and René J.F. Melis. "Validation of a Frailty Index from the Older Persons and Informal Caregivers Survey Minimum Data Set." *Journal of the American Geriatrics Society,* vol. 61, no. 9, 2013, pp. 1625–1627.

Macháčová, Kateřina, Hana Vaňková, Iva Holmerová, Inna Čábelková, and Ladislav Volicer. "Ratings of Activities of Daily Living in Nursing Home Residents: Comparison of Self- and Proxy Ratings with Actual Performance and the Impact of Cognitive Status." *European Journal of Ageing,* vol. 15, no. 4, 2018, pp. 349–358.

Margot-Cattin, Isabel, Nicolas Kuhne, Anders Kottorp, Malcolm Cutchin, Annika Öhman, and Louise Nygård. "Development of a Questionnaire to Evaluate Out-of-Home Participation for People with Dementia." *The American Journal of Occupational Therapy,* vol. 73, 2019, online only.

McKenzie, Karen, Dale Metcalfe, and George Murray. "A Review of Measures Used in the Screening, Assessment and Diagnosis of Dementia in People with an Intellectual Disability." *Journal of Applied Research in Intellectual Disabilities,* vol. 31, no. 5, 2018, pp. 725–742.

Robertson, Jane M. "Using Carer Biographical Narratives to Explore Factors Involved in Proxy Reporting of Quality of Life in People with Dementia." *Aging & Mental Health,* vol. 21, no. 4, 2017, pp. 416–425.

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.

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.

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.

Seelye, Adriana, Nora Mattek, Nicole Sharma, Thomas Riley, Johanna Austin, Katherine Wild, Hiroko H. Dodge, Emily Lore, and Jeffrey Kaye. "Weekly Observations of Online Survey Metadata Obtained Through Home Computer Use Allow for Detection of Changes in Everyday Cognition Before Transition to Mild Cognitive Impairment." *Alzheimer's & Dementia,* vol. 14, no. 2, 2018, pp. 187–194.

Sexton, Eithne, Mary-Ann O'Donovan, Niamh Mulryan, Philip McCallion, and Mary McCarron. "Whose Quality of Life? A Comparison of Measures of Self-Determination and Emotional Wellbeing in Research with Older Adults with and without Intellectual Disability." *Journal of Intellectual and Developmental Disability*, vol. 41, no. 4, 2016, pp. 324–337.

Tarzia, Laura, Michael Bauer, Deirdre Fetherstonhaugh, and Rhonda Nay. "Interviewing Older People in Residential Aged Care About Sexuality: Difficulties and Challenges." *Sexuality and Disability,* vol. 31, no. 4, 2013, pp. 361–371.

Teresi, Jeanne A., Katja Ocepek-Welikson, John A. Toner, Marjorie Kleinman, Mildred Ramirez, Joseph P. Eimicke, Barry J. Gurland, and Albert Siu. "Methodological Issues in Measuring Subjective Well-Being and Quality-of-Life: Applications to Assessment of Affect in Older, Chronically and Cognitively Impaired, Ethnically Diverse Groups Using the Feeling Tone Questionnaire." *Applied Research in Quality of Life,* vol. 12, no. 2, 2017, pp. 251–288.

Yang, Ming, Xiang Ding, and Birong Dong. "The Measurement of Disability in the Elderly: A Systematic Review of Self-Reported Questionnaires." *Journal of the American Medical Directors Association*, vol. 15, no. 2, 2014, pp. 150.e1–150.e9.

2. Developmental, Intellectual, and Other Cognitive Impairments

a. Developmental and Intellectual Disabilities

Adams, Dawn, Louise Handley, Mary Heald, Doug Simkiss, Alison Jones, Emily Walls, and Chris Oliver. "A Comparison of Two Methods for Recruiting Children with an Intellectual Disability." *Journal of Applied Research in Intellectual Disabilities,* vol. 30, no. 4, 2017, pp. 696–704.

Altman, Barbara M., Jennifer Madans, and Julie D. Weeks. "An Evaluation of the American Community Survey Indicators of Disability." *Disability and Health Journal,* vol. 10, no. 4, 2017, pp. 485–491.

Bakker-van Gijssel, Esther J., Peter L.B.J. Lucassen, Tim C. olde Hartman, Willem J.J. Assendelft, and Henny M.J. van Schrojenstein Lantman-de Valk. "Constructing a Health Assessment Questionnaire for People with Intellectual Disabilities: A Cognitive Interview Study." *Journal of Applied Research in Intellectual Disabilities,* 2019, online ahead of print.

Barrios, Polaris, Ricardo González, Sherrie Hanna, Angela Lunde, Julie Fields, Dona Locke, and Glenn Smith. "Priority of Treatment Outcomes for Caregivers and Patients with Mild Cognitive Impairment: Preliminary Analyses." *Neurology and Therapy,* vol. 5, no. 2, 2016, pp. 183–192.

Beail, Nigel, and Katie Williams. “Using Qualitative Methods in Research with People Who Have Intellectual Disabilities.” *Journal of Applied Research in Intellectual Disabilities,* vol. 27, no. 2, 2014, pp. 85–96.

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.

Bertelli, Marco O., Annamaria Bianco, Andrea Rossi, Michele Mancini, Giampaolo La Malfa, and Ivan Brown. “Impact of Severe Intellectual Disability on Proxy Instrumental Assessment of Quality of Life.” *Journal of Intellectual & Developmental Disability,* vol. 44, no. 3, 2019, pp.272–281.

Bigby, Christine, Patsie Frawley, and Paul Ramcharan. “A Collaborative Group Method of Inclusive Research.” *Journal of Applied Research in Intellectual Disabilities,* vol. 27, no. 1, 2014, pp. 54–64.

Blake, Grant A. “A New Protocol to Assess the Subjective Wellbeing of Adolescents with Intellectual Disability.” *Journal of Policy and Practice in Intellectual Disabilities,* vol. 14, no. 4, 2017, pp. 298–308.

Boström, Petra, Jakob Å. Johnels, Maria Thorson, and Malin Broberg. “Subjective Mental Health, Peer Relations, Family, and School Environment in Adolescents with Intellectual Developmental Disorder: A First Report of a New Questionnaire Administered on Tablet PCs.” *Journal of Mental Health Research in Intellectual Disabilities,* vol. 9, no. 4, 2016, pp. 207–231.

Brehmer-Rinderer, Barbara, Elisabeth L. Zeilinger, Ana Radaljevic, and Germain Weber. “The Vienna Frailty Questionnaire for Persons with Intellectual Disabilities—Revised.” *Research in Developmental Disabilities,* vol. 34, no. 6, 2013, pp. 1958–1965.

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.

Caldwell, Kate. “Dyadic Interviewing: A Technique Valuing Interdependence in Interviews with Individuals with Intellectual Disabilities.” *Qualitative Research,* vol. 14, no. 4, 2014, pp. 488–507.

Cihak, David F., Donald McMahon, Cate C. Smith, Rachel Wright, and Melinda M. Gibbons. “Teaching Individuals with Intellectual Disability to Email Across Multiple Device Platforms.” *Research in Developmental Disabilities,* vol. 36, 2015, pp. 645–656.

Clark, Lauren, Marjorie A. Pett, Elizabeth M. Cardell, Jia-Wen Guo, Erin Johnson, and Jia-Wen Guo. “Developing a Health-Related Quality-of-Life Measure for People with Intellectual Disability.” *Intellectual & Developmental Disabilities,* vol. 55, no. 3, 2017, pp. 140–153.

Clarke, Jason, Katherine Prescott, and Rebecca Milne. “How Effective Is the Cognitive Interview When Used with Adults with Intellectual Disabilities Specifically with Conversation Recall?” *Journal of Applied Research in Intellectual Disabilities,* vol. 26, no. 6, 2013, pp. 546–556.

Curtin, Carol, Linda G. Bandini, Aviva Must, Sarah Phillips, Melissa C.T. Maslin, Charmaine Lo, James M. Gleason, Richard K. Fleming, and Heidi I. Stanish. "Including Youth with Intellectual Disabilities in Health Promotion Research: Development and Reliability of a Structured Interview to Assess the Correlates of Physical Activity Among Youth." *Journal of Applied Research in Intellectual Disabilities,* vol. 29, no. 4, 2016, pp. 378–386.

Dada, Shakila, Anna K. Andersson, Adele May, Elisabeth E. Andersson, Mats Granlund, and Karina Huus. "Agreement Between Participation Ratings of Children with Intellectual Disabilities and Their Primary Caregivers." *Research in Developmental Disabilities,* vol. 104, 2020, article no. 103715.

Daniel, Matthew R., Susan A. Sadek, and Peter E. Langdon. "The Reliabilty and Validity of a Revised Version of the How I Think Questionnaire for Men Who Have Intellectual Disabilities." *Psychology, Crime & Law,* vol. 24, no. 4, 2018, pp. 379–390.

de Geus-Neelen, Karin C.J.M., Wietske M.W.J. van Oorsouw, Lex A.H.C. Hendriks, and Petri J.C.M. Embregts. "Perceptions of Staff and Family of the Quality of Life of People with Severe to Profound Intellectual Disability." *Journal of Intellectual & Developmental Disability,* vol. 44, no. 1, 2019, pp. 42–50.

Dean, Katherine, Crispin Jenkinson, Gordon Wilcock, and Zuzana Walker. "The Development and Validation of a Patient-Reported Quality of Life Measure for People with Mild Cognitive Impairment." *International Psychogeriatrics,* vol. 26, no. 3, 2014, pp. 487–497.

Dean, Katherine, Zuzana Walker, and Crispin Jenkinson. "Data Quality, Floor and Ceiling Effects, and Test-Retest Reliability of the Mild Cognitive Impairment Questionnaire." *Patient Related Outcome Measures,* vol. 9, 2018, pp. 43–47.

Dekkers, Laura M.S., Anika Bexkens, Abe D. Hofman, Paul D. Boeck, Annematt L. Collot d'Escury, and Hilde M. Huizenga. "Formal Modeling of the Resistance to Peer Influence Questionnaire: A Comparison of Adolescent Boys and Girls With and Without Mild-to-Borderline Intellectual Disability." *Assessment,* vol. 26, no. 6, 2019, pp. 1070–1083.

Dorozenko, Kate P., Brian J. Bishop, and Lynne D. Roberts. "Fumblings and Faux Pas: Reflections on Attempting to Engage in Participatory Research with People with an Intellectual Disability." *Journal of Intellectual & Developmental Disability,* vol. 41, no. 3, 2016, pp. 197–208.

Eccles, Alicia, Reg Morris, and Ian Kneebone. "Psychometric Properties of the Behavioural Outcomes of Anxiety Questionnaire in Stroke Patients with Aphasia." *Clinical Rehabilitation,* vol. 31, no. 3, 2017, pp. 369–378.

Emerson, Eric, David Felce, and Roger J. Stancliffe. "Issues Concerning Self-Report Data and Population-Based Data Sets Involving People with Intellectual Disabilities." *Intellectual & Developmental Disabilities,* vol. 51, no. 5, 2013, pp. 333–348.

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 and Psychiatric Epidemiology.* Published ahead of print, September 14, 2020.

Ferretti, Lisa A., and Philip McCallion. "Translating the Chronic Disease Self-Management Program for Community-Dwelling Adults with Developmental Disabilities." *Journal of Aging & Health,* vol. 31, suppl. 10, 2019, pp. 22S–38S.

Flynn, Samantha, Leen Vereenooghe, Richard P. Hastings, Dawn Adams, Sally-Ann Cooper, Nick Gore, Chris Hatton, Kerry Hood, Andrew Jahoda, Peter E. Langdon, Rachel McNamara, Chris Oliver, Ashok Roy, Vasiliki Totsika, and Jane Waite. "Measurement Tools for Mental Health Problems and Mental Well-Being in People with Severe or Profound Intellectual Disabilities: A Systematic Review." *Clinical Psychology Review,* vol. 57, 2017, pp. 32–44.

Frankena, T.K., J. Naaldenberg, M. Cardol, J.V. Meijering, G. Leusink, and H.J.M. van Schrojenstein Lantman-de Valk. "Exploring Academics' Views on Designs, Methods, Characteristics and Outcomes of Inclusive Health Research with People with Intellectual Disabilities: A Modified Delphi Study." *BMJ Open,* vol. 6, no. 8, 2016, online only.

Frankena, Tessa K., Jenneken Naaldenberg, Hilde Tobi, Anneke van der Cruijsen, Henk Jansen, Henry van Schrojenstein Lantman - de Valk, Geraline Leusink, and Mieke Cardol. "A Membership Categorization Analysis of Roles, Activities and Relationships in Inclusive Research Conducted by Co-Researchers with Intellectual Disabilities." *Journal of Applied Research in Intellectual Disabilities,* vol. 32, no. 3, 2019, pp. 719–729.

Frankena, Tessa K., Jenneken Naaldenberg, Nienke Bekkema, Henny J.M. van Schrojenstein Lantman-de Valk, Mieke Cardol, and Geraline Leusink. "An Exploration of the Participation of People with Intellectual Disabilities in Research-a Structured Interview Survey." *Journal of Applied Research in Intellectual Disabilities*, vol. 31, no. 5, 2018, pp. 942–947.

Frielink, Noud, and Petri Embregts. "Modification of Motivational Interviewing for Use with People with Mild Intellectual Disability and Challenging Behaviour." *Journal of Intellectual & Developmental Disability,* vol. 38, no. 4, 2013, pp. 279–291.

Georgiadou, Ioanna, Anastasia Vlachou, and Panayiota Stavroussi. "Development of the 'Special-Vocational-Education-Service-Quality Scale': Listening to the Voices of Students with Intellectual Disability." *Quality Assurance in Education: An International Perspective,* vol. 28, no. 2, 2020, pp. 89–103.

Gómez, Laura E., M. L. Morán, M. Á. Alcedo, Víctor B. Arias, and Miguel-Ángel Verdugo. "Addressing Quality of Life of Children with Autism Spectrum Disorder and Intellectual Disability." *Intellectual & Developmental Disabilities,* vol. 58, no. 5, 2020, pp. 393–408.

Hall, Natalie, Marie-Anne Durand, and Silvana E. Mengoni. "'...Their Opinions Mean Something': Care Staff's Attitudes to Health Research Involving People with Intellectual Disabilities." *British Journal of Learning Disabilities,* vol. 45, no. 3, 2017, pp. 198–207.

Havercamp, Susan M., Gloria L. Krahn, Sheryl A. Larson, Glenn Fujiura, Tawara D. Goode, and Barbara L. Kornblau. "Identifying People with Intellectual and Developmental Disabilities in National Population Surveys." *Intellectual and Developmental Disabilities,* vol. 57, no. 5, 2019, pp. 376–389.

Heffron, Jenna L., Natasha A. Spassiani, Amber M. Angell, and Joy Hammel. “Using Photovoice as a Participatory Method to Identify and Strategize Community Participation with People with Intellectual and Developmental Disabilities.” *Scandinavian Journal of Occupational Therapy,* vol. 25, no. 5, 2018, pp. 382–395.

Ho, Lily Y. W., Kenny C. W. Chin, Connie Y. Y. Fung, and Claudia K. Y. Lai. “Validation of the Chinese Non-pharmacological Therapy Experience Scale in Persons with Intellectual Disability.” *Nursing Open,* vol. 7, no. 1, 2020, pp. 390–397.

Hollomotz, Andrea. “Successful Interviews with People with Intellectual Disability.” *Qualitative Research,* vol. 18, no. 2, 2018, pp. 153–170.

Hughes, Rosemary B., Susan Robinson-Whelen, Rebecca Goe, Michelle Schwartz, Lisa Cesal, Kimberly B. Garner, Katie Arnold, Tina Hunt, and Katherine E. McDonald. “‘I Really Want People to Use Our Work to Be Safe’…Using Participatory Research to Develop a Safety Intervention for Adults with Intellectual Disability.” *Journal of Intellectual Disabilities,* vol. 24, no. 3, 2020, pp. 309–325.

Ipsen, Catherine, Cathy Chambless, Noelle Kurth, Sara McCormick, Rebecca Goe, and Jean Hall. “Underrepresentation of Adolescents with Respiratory, Mental Health, and Developmental Disabilities Using American Community Survey (ACS) Questions.” *Disability and Health Journal*, vol. 11, no. 3, 2018, pp. 447–450.

Jenaro, Cristina, Noelia Flores, Maribel Cruz, Ma C. Pérez, Vanessa Vega, and Ví Torres. “Internet and Cell Phone Usage Patterns Among Young Adults with Intellectual Disabilities.” *Journal of Applied Research in Intellectual Disabilities,* vol. 31, no. 2, 2018, pp. 259–272.

Jen-Yi, Li, Malathy Krishnasamy, and Chen Der-Thanq. “Research with Persons with Intellectual Disabilities: An Inclusive Adaptation of Tourangeau’s Model.” *Alter,* vol. 9, no. 4, 2015, pp. 304–316.

Kaley, Alexandra, Chris Hatton, and Christine Milligan. “More than Words: The Use of Video in Ethnographic Research with People with Intellectual Disabilities.” *Qualitative Health Research,* 2018, online ahead of print.

Kaley, Alexandra, Chris Hatton, and Christine Milligan. “More than Words: The Use of Video in Ethnographic Research with People with Intellectual Disabilities.” *Qualitative Health Research,* vol. 29, no. 7, 2019, pp. 931–943.

Kang, Ya-Shu, Li-Yu Chen, Shaou-Gang Miaou, and Yao-Jen Chang. “A Community-Based Participatory Approach to Developing Game Technology to Provide Greater Accessibility for Children with Intellectual Disabilities.” *Systemic Practice and Action Research,* 2020.

Kocman, A., and G. Weber. “Concepts of Job Satisfaction in People with Intellectual Disability.” *Journal of Intellectual Disability Research,* vol. 62, no. 9, 2018, pp. 814–819.

Kozlowski, Allan J., Ritika Singh, David Victorson, Ana Miskovic, Jin-Shei Lai, Richard L. Harvey, David Cella, and Allen W. Heinemann. “Agreement Between Responses from Community-Dwelling Persons with Stroke and Their Proxies on the NIH Neurological Quality of Life (Neuro-QoL) Short Forms.” *Archives of Physical Medicine and Rehabilitation,* vol. 96, no. 11, 2015, pp. 1986–1992.

Kramer, Jessica M., and Ariel E. Schwartz. "Development of the Pediatric Disability Inventory-Patient Reported Outcome (PEDI-PRO) Measurement Conceptual Framework and Item Candidates." *Scandinavian Journal of Occupational Therapy,* vol. 25, no. 5, 2018, pp. 335–346.

Kramer, Jessica M., Ariel E. Schwartz, Destiny Watkins, Micah Peace, Sara Luterman, Ben Barnhart, Jacob Bouma-Sims, Jessica Riley, Janet Shouse, Ravita Maharaj, Cordelia R. Rosenberg, Karyn Harvey, Juliana Huereña, Katy Schmid, and Jennifer S. Alexander. "Improving Research and Practice: Priorities for Young Adults with Intellectual/Developmental Disabilities and Mental Health Needs." *Journal of Mental Health Research in Intellectual Disabilities,* 2019, online ahead of print.

Liljenquist, K., W. Coster, J. Kramer, and Z. Rossetti. "Feasibility of the Participatory Experience Survey and the Setting Affordances Survey for Use in Evaluation of Programmes Serving Youth with Intellectual and Developmental Disabilities." *Child: Care, Health and Development,* vol. 43, no. 4, 2017, pp. 511–517.

Macháčová, Kateřina, Hana Vaňková, Iva Holmerová, Inna Čábelková, and Ladislav Volicer. "Ratings of Activities of Daily Living in Nursing Home Residents: Comparison of Self- and Proxy Ratings with Actual Performance and the Impact of Cognitive Status." *European Journal of Ageing,* vol. 15, no. 4, 2018, pp. 349–358.

Markowitz, Leslie A., Charina Reyes, Rebecca A. Embacher, Leslie L. Speer, Nancy Roizen, and Thomas W. Frazier. "Development and Psychometric Evaluation of a Psychosocial Quality-of-Life Questionnaire for Individuals with Autism and Related Developmental Disorders." *Autism,* vol. 20, no. 7, 2016, pp. 832–844.

McDonald, Katherine E., and Erin Stack. "You Say You Want a Revolution: An Empirical Study of Community-Based Participatory Research with People with Developmental Disabilities." *Disability and Health Journal,* vol. 9, no. 2, 2016, pp. 201–207.

McKenzie, Karen, Dale Metcalfe, and George Murray. "A Review of Measures Used in the Screening, Assessment and Diagnosis of Dementia in People with an Intellectual Disability." *Journal of Applied Research in Intellectual Disabilities,* vol. 31, no. 5, 2018, pp. 725–742.

McKenzie, Karen, George Murray, Aja Murray, Rachel Martin, Yasmin Tanfield, Lauren Delahunty, Linda Hutton, Kara R. Murray, and Anne O'Hare. "Screening for Intellectual Disability with the Child and Adolescent Intellectual Screening Questionnaire: A Modified Delphi Approach." *Developmental Medicine & Child Neurology,* vol. 61, no. 8, 2019, pp. 979–983.

McKenzie, Karen, George Murray, Linda Hutton, Aja Murray, Lauren Delahunty, Anne O'Hare, and Kara Murray. "Child and Adolescent Intellectual Disability Screening Questionnaire to Identify Children with Intellectual Disability." *Developmental Medicine & Child Neurology,* vol. 61, no. 4, 2019, pp. 444–450.

Mevissen, Liesbeth, Robert Didden, Ad de Jongh, and Hubert Korzilius. "Assessing Posttraumatic Stress Disorder in Adults with Mild Intellectual Disabilities or Borderline Intellectual Functioning." *Journal of Mental Health Research in Intellectual Disabilities,* vol. 13, no. 2, 2020, pp. 110–126.

Mileviciute, I., and S.L. Hartley. "Self-Reported Versus Informant-Reported Depressive Symptoms in Adults with Mild Intellectual Disability." *Journal of Intellectual Disability Research*, vol. 59, no. 2, 2015, pp. 158–169.

Milne, Rebecca, Stefanie J. Sharman, Martine B. Powell, and Sarah Mead. "Assessing the Effectiveness of the Cognitive Interview for Children with Severe Intellectual Disabilities." *International Journal of Disability, Development and Education,* vol. 60, no. 1, 2013, pp. 18–29.

Morgan, Michelle F., Karen B. Moni, and Monica Cuskelly. "The Development of Research Skills in Young Adults with Intellectual Disability in Participatory Research." *International Journal of Disability, Development and Education,* vol. 62, no. 4, 2015, pp. 438–457.

Morin, D., P. Valois, A.G. Crocker, and C. Robitaille. "Development and Psychometric Properties of the Attitudes Toward Intellectual Disability Questionnaire – Short Form." *Journal of Intellectual Disability Research,* vol. 63, no. 6, 2019, pp. 539–547.

Moss, Sarah J. and Stanislaw H. Czyz. "Level of Agreement Between Physical Activity Levels Measured by ActiHeart and the International Physical Activity Questionnaire in Persons with Intellectual Disability." *Disability and Rehabilitation,* vol. 40, no. 3, 2018, pp. 360–366.

Nicolaidis, Christina, Dora M. Raymaker, Katherine E. McDonald, Emily M. Lund, Sandra Leotti, Steven K. Kapp, Marsha Katz, Leanne M. Beers, Clarissa Kripke, Joelle Maslak, et al. "Creating Accessible Survey Instruments for Use with Autistic Adults and People with Intellectual Disability: Lessons Learned and Recommendations." *Autism in Adulthood: Challenges and Management,* vol. 2, no. 1, 2020, pp. 61–76.

Nicolaidis, Christina, Dora Raymaker, Marsha Katz, Mary Oschwald, Rebecca Goe, Sandra Leotti, Leah Grantham, Eddie Plourde, Janice Salomon, Rosemary B. Hughes, and Laurie E. Powers. "Community-Based Participatory Research to Adapt Health Measures for Use by People with Developmental Disabilities." *Progress in Community Health Partnerships: Research, Education, and Action,* vol. 9, no. 2, 2015, pp. 157–170.

Northway, Ruth, Joyce Howarth, and Lynne Evans. "Participatory Research, People with Intellectual Disabilities and Ethical Approval: Making Reasonable Adjustments to Enable Participation." *Journal of Clinical Nursing,* vol. 24, no. 3–4, 2015, pp. 573–581.

O'Brien, Patricia, Roy McConkey, and Edurne García-Iriarte. "Co-Researching with People Who Have Intellectual Disabilities: Insights from a National Survey." *Journal of Applied Research in Intellectual Disabilities,* vol. 27, no. 1, 2014, pp. 65–75.

O'Keeffe, Lynsey, Suzanne Guerin, John McEvoy, Karen Lockhart, and Philip Dodd. "The Process of Developing Self-Report Measures in Intellectual Disability: A Case Study of a Complicated Grief Scale." *British Journal of Learning Disabilities,* vol. 47, no. 2, 2019, pp. 134–144.

Oschwald, Mary, Sandy Leotti, Dora Raymaker, Marsha Katz, Rebecca Goe, Mark Harviston, Annie Wallington, Lisa Howard, Leanne Beers, Christina Nicolaidis, Susan Robinson-Whelen, Rosemary B. Hughes, Emily Lund, and Laurie E. Powers. "Development of an Audio-Computer Assisted Self-Interview to Investigate Violence and Health in the Lives of Adults with Developmental Disabilities." *Disability and Health Journal,* vol. 7, no. 3, 2014, pp. 292–301.

Ottmann, Goetz, and Jenny Crosbie. "Mixed Method Approaches in Open-Ended, Qualitative, Exploratory Research Involving People with Intellectual Disabilities: A Comparative Methods Study." *Journal of Intellectual Disabilities,* vol. 17, no. 3, 2013, pp. 182–197.

Pérez-Cruzado, D., and A.I. Cuesta-Vargas. "Energy Expenditure Measured with Accelerometers and Self-Report Questionnaire in People with Intellectual Disabilities." *Journal of Intellectual Disability Research,* vol. 62, no. 8, 2018, pp. 701–708.

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.

Perry, Adrienne, Meisha Charles, Busi Ncube, and Jonathan Weiss. "The GO4KIDDS School Satisfaction Scale." *Journal of Applied Research in Intellectual Disabilities,* vol. 32, no. 2, 2019, pp. 471–474.

Povee, Kate, Brian J. Bishop, and Lynne D. Roberts. "The Use of Photovoice with People with Intellectual Disabilities: Reflections, Challenges and Opportunities." *Disability & Society,* vol. 29, no. 6, 2014, pp. 893–907.

Prior, Sarah, Andrea Miller, Steven Campbell, Karen Linegar, and Gregory Peterson. "The Challenges of Including Patients with Aphasia in Qualitative Research for Health Service Redesign: Qualitative Interview Study." *Journal of Participatory Medicine,* vol. 12, no. 1, 2020, article no. e12336.

Puyalto, Carol, Maria Pallisera, Judit Fullana, and Montserrat Vilà. "Doing Research Together: A Study on the Views of Advisors with Intellectual Disabilities and Non-Disabled Researchers Collaborating in Research." *Journal of Applied Research in Intellectual Disabilities,* vol. 29, no. 2, 2016, pp. 146–159.

Raczka, Roman, Kate Theodore, and Janice Williams. "An Initial Validation of a New Quality of Life Measure for Adults with Intellectual Disability: The Mini-MANS-LD." *Journal of Intellectual Disabilities,* vol. 24, no. 2, 2020, pp. 177–193.

Raghunath, Nisha, Jessamyn Dahmen, Katelyn Brown, Diane Cook, and Maureen Schmitter-Edgecombe. "Creating a Digital Memory Notebook Application for Individuals with Mild Cognitive Impairment to Support Everyday Functioning." *Disability and Rehabilitation: Assistive Technology,* 2019, online ahead of print.

Rand, Stacey, James Caiels, Grace Collins, and Julien Forder. "Developing a Proxy Version of the Adult Social Care Outcome Toolkit (ASCOT)." *BMC Health and Quality of Life Outcomes,* vol. 15, no. 108, 2017, online only.

Rice, L.J., E. Emerson, K.M. Gray, P. Howlin, B.J. Tonge, G.L. Warner, and S.L. Einfeld. “Concurrence of the Strengths and Difficulties Questionnaire and Developmental Behaviour Checklist Among Children with an Intellectual Disability.” *Journal of Intellectual Disability Research,* vol. 62, no. 2, 2018, pp. 150–155.

Riches, Tanya N., and Patricia M. O'Brien. “Can We Publish Inclusive Research Inclusively? Researchers with Intellectual Disabilities Interview Authors of Inclusive Studies.” *British Journal of Learning Disabilities,* vol. 48, no. 4, 2020, pp. 272–280.

Rix, Jonathan, Helena G. Carrizosa, Jane Seale, Kieron Sheehy, and Simon Hayhoe. “The While of Participation: A Systematic Review of Participatory Research Involving People with Sensory Impairments and/or Intellectual Impairments.” *Disability & Society,* 2019, online ahead of print.

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.

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.

Schützwohl, Matthias, Elke Voß, Hans J. Salize, Maja Stiawa, Bernd Puschner, and Andrea Koch. “Self- and Proxy-Rated Needs in Adults with Mild to Moderate Intellectual Disabilities: Perspective Matters.” *Journal of Applied Research in Intellectual Disabilities,* vol. 31, no. 2, 2018, pp. 285–295.

Schwartz, Ariel E., and Jessica M. Kramer. “Inclusive Approaches to Developing Content Valid Patient-Reported Outcome Measure Response Scales for Youth with Intellectual/Developmental Disabilities.” *British Journal of Learning Disabilities.* Published ahead of print, October 6, 2020.

Schwartz, Ariel E., Jessica M. Kramer, Ellen S. Cohn, and Katherine E. McDonald. “‘That Felt Like Real Engagement': Fostering and Maintaining Inclusive Research Collaborations with Individuals with Intellectual Disability” *Qualitative Health Research,* vol. 30, no. 2, 2020, pp. 236–249.

Scott, Haleigh M., and Susan M. Havercamp. “Comparison of Self- and Proxy Report of Mental Health Symptoms in People with Intellectual Disabilities*.” Journal of Mental Health Research in Intellectual Disabilities,* vol. 11, no. 2, 2018, pp. 143–156.

Scott, Haleigh M., and Susan M. Havercamp. “Comparisons of Self and Proxy Report on Health-Related Factors in People with Intellectual Disability.” *Journal of Applied Research in Intellectual Disabilities,* vol. 31, no. 5, 2018, pp. 927–936.

Sexton, Eithne, Mary-Ann O'Donovan, Niamh Mulryan, Philip McCallion, and Mary McCarron. "Whose Quality of Life? A Comparison of Measures of Self-Determination and Emotional Wellbeing in Research with Older Adults with and without Intellectual Disability." *Journal of Intellectual and Developmental Disability,* vol. 41, no. 4, 2016, pp. 324–337.

Sigstad, Hanne M.H. "Characteristic Interviews, Different Strategies: Methodological Challenges in Qualitative Interviewing Among Respondents with Mild Intellectual Disabilities." *Journal of Intellectual Disabilities,* vol. 18, no. 2, 2014, pp. 188–202.

Sigstad, Hanne M.H., and Veerle Garrels. "Facilitating Qualitative Research Interviews for Respondents with Intellectual Disability." *European Journal of Special Needs Education,* vol. 33, no. 5, 2018, pp. 692–706.

Silva, Soraia M., Fernanda I. Corrêa, Gabriela S. Pereira, Christina Danielli Coelho de Morais Faria, and João C.F. Corrêa. "Construct Validity of the Items on the Stroke Specific Quality of Life (SS-QOL) Questionnaire that Evaluate the Participation Component of the International Classification of Functioning, Disability and Health." *Disability and Rehabilitation,* vol. 40, no. 2, 2018, pp. 225–231.

Simões, Cristina, and Sofia Santos. "The Quality of Life Perceptions of People with Intellectual Disability and Their Proxies." *Journal of Intellectual & Developmental Disability*, vol. 41, no. 4, 2016, pp. 311–323.

St. John, Brittany, Iulia Mihaila, Katelyn Dorrance, Leann S. DaWalt, and Karla K. Ausderau. "Reflections from Co-Researchers with Intellectual Disability: Benefits to Inclusion in a Research Study Team." *Intellectual and Developmental Disabilities,* vol. 56, no. 4, 2018, pp. 251–262.

Stack, Erin E., and Katherine McDonald. "We Are 'Both in Charge, the Academics and Self-Advocates': Empowerment in Community-Based Participatory Research." *Journal of Policy and Practice in Intellectual Disabilities,* vol. 15, no. 1, 2018, pp. 80–89.

Stancliffe, Roger J., Renáta Tichá, Sheryl A. Larson, Amy S. Hewitt, and Derek Nord. "Responsiveness to Self-Report Interview Questions by Adults with Intellectual and Developmental Disability." *Intellectual and Developmental Disabilities*, vol. 53, no. 3, 2015, pp. 163–181.

Stavrakantonaki, Marina, and Timothy P. Johnson. "Effects of Rosa's Law on Intellectual-Disability Reporting." *Public Opinion Quarterly,* vol. 82, no. 3, 2018, pp. 593–604.

Stevenson, Miriam. "Participatory Data Analysis Alongside Co-Researchers Who Have Down Syndrome." *Journal of Applied Research in Intellectual Disabilities,* vol. 27, no. 1, 2014, pp. 23–33.

Strnadová, Iva, and Jan Walmsley. "Peer-Reviewed Articles on Inclusive Research: Do Co-Researchers with Intellectual Disabilities Have a Voice?" *Journal of Applied Research in Intellectual Disabilities,* vol. 31, no. 1, 2018, pp. 132–141.

Strnadová, Iva, Jan Walmsley, Kelley Johnson, and Therese M. Cumming. "Diverse Faces of Inclusive Research: Reflecting on Three Research Studies." *Scandinavian Journal of Disability Research,* vol. 18, no. 1, 2016, pp. 52–64.

Strnadová, Iva, Therese M. Cumming, Marie Knox, and Trevor Parmenter. "Building an Inclusive Research Team: The Importance of Team Building and Skills Training." *Journal of Applied Research in Intellectual Disabilities*, vol. 27, no. 1, 2014, pp. 13–22.

Swatt, Adam J., Ariel E. Schwartz, and Jessica M. Kramer. "Youth's Perspective of Responsibility: Exploration of a Construct for Measurement with Youth with Developmental Disabilities." *Physical & Occupational Therapy in Pediatrics,* vol. 39, no. 2, 2019, pp. 204–216.

Takenoshita, S., S. Terada, R. Kuwano, T. Inoue, T. Kurozumi, A. Choju, S. Suemitsu, and N. Yamada. "Validation of the Japanese Version of the Dementia Screening Questionnaire for Individuals with Intellectual Disabilities." *Journal of Intellectual Disability Research,* vol. 64, no. 12, 2020, pp. 970–979.

Teresi, Jeanne A., Katja Ocepek-Welikson, John A. Toner, Marjorie Kleinman, Mildred Ramirez, Joseph P. Eimicke, Barry J. Gurland, and Albert Siu. "Methodological Issues in Measuring Subjective Well-Being and Quality-of-Life: Applications to Assessment of Affect in Older, Chronically and Cognitively Impaired, Ethnically Diverse Groups Using the Feeling Tone Questionnaire." *Applied Research in Quality of Life,* vol. 12, no. 2, 2017, pp. 251–288.

Turnpenny, Agnes, James Caiels, Beckie Whelton, Lisa Richardson, Julie Beadle-Brown, Tanya Crowther, Julien Forder, Joanna Apps, and Stacey Rand. "Developing an Easy Read Version of the Adult Social Care Outcomes Toolkit (ASCOT)." *Journal of Applied Research in Intellectual Disabilities,* vol. 31, no. 1, 2018, pp. e36–e48.

Verseghy, Judy, Lynda Atack, and Janet Maher. "Key Considerations When Interviewing Individuals with Expressive Language Difficulties." *Qualitative Research,* vol. 20, no. 6, 2020, pp. 960–970.

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

Walmsley, Jan, Iva Strnadová, and Kelley Johnson. "The Added Value of Inclusive Research." *Journal of Applied Research in Intellectual Disabilities,* vol. 31, no. 5, 2018, pp. 751–759.

Wilson, Nathan J., Yu-Wei Chen, Natasha Mahoney, Angus Buchanan, Anne Marks, and Reinie Cordier. "Experience Sampling Method and the Everyday Experiences of Adults with Intellectual Disability: A Feasibility Study." *Journal of Applied Research in Intellectual Disabilities,* vol. 33, no. 6, 2020, pp. 1328–1339.

Wright-Bevans, Katie, Michael Richards, Mary Brydon-Miller, Michael Kral, and Alfredo Ortiz Aragón. "Using PAR to Promote Social Justice for Older People and People with Intellectual Disabilities." *International Review of Qualitative Research,* vol. 13, no. 2, 2020, pp. 219–232.

Wyman, Joshua D., Jennifer Lavoie, and Victoria Talwar. "Best Practices for Interviewing Children with Intellectual Disabilities in Maltreatment Cases." *Exceptionality,* vol. 27, no. 3, 2019, pp. 167–184.

b. Dementia

Adams, M. "Results and Their Implications from Comparing Respondents and Proxy Responses for Non-Respondents with Cognitive Difficulties on a Telephone Survey." *Disability and Health Journal,* vol. 10, no. 1, 2017, pp. 131–138.

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.

Amspoker, Amber B., A. Lynn Snow, Brenna N. Renn, Phoebe Block, Sabrina Pickens, Robert O. Morgan, and Mark E. Kunik. "Patient Versus Informal Caregiver Proxy Reports of Pain Interference in Persons with Dementia." *Journal of Applied Gerontology.* Published ahead of print, February 6, 2020.

Arons, Alexander, Paul Krabbe, Gert Wilt, Marcel Olde Rikkert, and Eddy Adang. "Visual Analogue Scales: Scale Recalibration by Patients with Dementia and Their Proxies." *Quality of Life Research,* vol. 22, no. 5, 2013, pp. 979–986.

Athilingam, Ponrathi, Constance Visovsky, Amanda F. Elliott, and Philip J. Rogal. "Cognitive Screening in Persons with Chronic Diseases in Primary Care: Challenges and Recommendations for Practice." *American Journal of Alzheimer's Disease and Other Dementias*, vol. 30, no. 6, 2015, pp. 547–558.

Bentvelzen, Adam C., John D. Crawford, Adam Theobald, Kate Maston, Melissa J. Slavin, Simone Reppermund, Kristan Kang, Katya Numbers, Henry Brodaty, Perminder Sachdev, et al. "Validation and Normative Data for the Modified Telephone Interview for Cognitive Status: The Sydney Memory and Ageinggar Study." *Journal of the American Geriatrics Society,* vol. 67, no. 10, 2019, pp. 2108–2115.

Bruno, D., A. Slachevsky, N. Fiorentino, D. S. Rueda, G. Bruno, A. R. Tagle, L. Olavarria, P. Flores, P. Lillo, M. Roca, and T. Torralva. "Argentinian/Chilean Validation of the Spanish-Language Version of Addenbrooke's Cognitive Examination III for Diagnosing Dementia." *Neurología (English Edition),* vol. 35, no. 2, 2020, pp. 82–88.

Carvalho, Janessa O., Beth Springate, Rachel A. Bernier, and Jennifer Davis. "Psychometrics of the AAN Caregiver Driving Safety Questionnaire and Contributors to Caregiver Concern About Driving Safety in Older Adults." *International Psychogeriatrics,* vol. 30, no. 3, 2018, pp. 355–364.

Chen, Hsin-Hao, Fang-Ju Sun, Tzu-Lin Yeh, Hsueh-Erh Liu, Hsiu-Li Huang, Benjamin I. Kuo, and Hsin-Yi Huang. "The Diagnostic Accuracy of the Ascertain Dementia 8 Questionnaire for Detecting Cognitive Impairment in Primary Care in the Community, Clinics and Hospitals: A Systematic Review and Meta-Analysis." *Family Practice,* vol. 35, no. 3, 2018, pp. 239–246.

Cridland, Elizabeth K., Lyn Phillipson, Christopher Brennan-Horley, and Kate Swaffer. "Reflections and Recommendations for Conducting In-Depth Interviews with People with Dementia." *Qualitative Health Research,* vol. 26, no. 13, 2016, pp. 1774–1786.

Davies, Katharine. “Conceptualizing Participation and Communication Disorder in Dementia Research.” *Perspectives of the ASHA Special Interest Groups,* vol. 5, no. 1, 2020, pp. 256–260.

Davis, Jennifer C., Ging-Yuek Hsiung, Stirling Bryan, Claudia Jacova, Patrizio Jacova, Michelle Munkacsy, Winnie Cheung, Philip Lee, and Teresa Liu-Ambrose. “Agreement Between Patient and Proxy Assessments of Quality of Life Among Older Adults with Vascular Cognitive Impairment Using the EQ-5D-3L and ICECAP-O.” *PLoS ONE,* vol. 11, no. 4, 2016, online only.

Digby, Robin, Susan Lee, and Allison Williams. “Interviewing People with Dementia in Hospital: Recommendations for Researchers.” *Journal of Clinical Nursing,* vol. 25, no. 7–8, 2016, pp. 1156–1165.

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.

Facal, David, Miguel A.R. Carabias, Arturo X. Pereiro, Cristina Lojo-Seoane, María Campos-Magdaleno, Roos J. Jutten, Sietske A.M. Sikkes, and Onésimo Juncos-Rabadán. “Assessing Everyday Activities Across the Dementia Spectrum with the Amsterdam IADL Questionnaire.” *Current Alzheimer Research,* vol. 15, no. 13, 2018, pp. 1261–1266.

Farina, Nicolas, Laura J. Hughes, Amber Watts, and Ruth G. Lowry. “Use of Physical Activity Questionnaires in People with Dementia: A Scoping Review.” *Journal of Aging and Physical Activity*, 2018, pp. 1–24.

Gomez-Gallego, M., J. Gomez-Garcia, and E. Ato-Lozano. “Addressing the Bias Problem in the Assessment of the Quality of Life of Patients with Dementia: Determinants of the Accuracy and Precision of the Proxy Ratings.” *The Journal of Nutrition, Health & Aging*, vol. 19, no. 3, 2015, pp. 365–372.

Gordon, Mark F., William R. Lenderking, Amy Duhig, Julie Chandler, J. Jason Lundy, David S. Miller, Elisabeth Piault-Louis, Rachelle S. Doody, Douglas Galasko, Serge Gauthier, and Lori Frank. “Development of a Patient-Reported Outcome Instrument to Assess Complex Activities of Daily Living and Interpersonal Functioning in Persons with Mild Cognitive Impairment: The Qualitative Research Phase.” *Alzheimer’s & Dementia*, vol. 12, no. 1, 2016, pp. 75–84.

Gruters, Angélique A.A., Inez H.G.B. Ramakers, Frans R.J. Verhey, Sebastian Köhler, Roy P.C. Kessels, Marjolein E. de Vugt, and Katherine Gifford. “Association Between Proxy- or Self-Reported Cognitive Decline and Cognitive Performance in Memory Clinic Visitors.” *Journal of Alzheimer’s Disease,* vol. 70, no. 4, 2019, pp. 1225–1239.

Hendriks, A.A. Jolijn, Sarah C. Smith, Theopisti Chrysanthaki, and Nick Black. “Reliability and Validity of a Self-Administration Version of DEMQOL-Proxy.” *International Journal of Geriatric Psychiatry,* vol. 32, no. 7, 2017, pp. 734–741.

Jakobsson, Elin, Louise Nygård, Anders Kottorp, Cecilia B. Olsson, and Camilla Malinowsky. "The Use of Everyday Technology: A Comparison of Older Persons with Cognitive Impairments' Self-Reports and their Proxies' Reports." *British Journal of Occupational Therapy,* 2020.

Jongsma, Karin, Julia Perry, Silke Schicktanz, and Katrin Radenbach. "Motivations for People with Cognitive Impairment to Complete an Advance Research Directive – A Qualitative Interview Study." *BMC Psychiatry,* vol. 20, no. 1, 2020, pp. 1–9.

Kotwal, Ashwin A., Philip Schumm, David W. Kern, Martha K. McClintock, Linda J. Waite, Joseph W. Shega, Megan J. Huisingh-Scheetz, and William Dale. "Evaluation of a Brief Survey Instrument for Assessing Subtle Differences in Cognitive Function Among Older Adults." *Alzheimer Disease and Associated Disorders,* vol. 29, no. 4, 2015, pp. 317–324.

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.

Lindgren, Noora, Juha O. Rinne, Teemu Palviainen, Jaakko Kaprio, and Eero Vuoksimaa. "Prevalence and Correlates of Dementia and Mild Cognitive Impairment Classified with Different Versions of the Modified Telephone Interview for Cognitive Status (TICS–m)." *International Journal of Geriatric Psychiatry,* vol. 34, no. 12, 2019, pp. 1883–1891.

Littlejohn, Jenna, Daniel Blackburn, and Annalena Venneri. "Understanding the Links Between Hearing Impairment and Dementia: Development and Validation of the Social and Emotional Impact of Hearing Impairment (SEI-HI) Questionnaire." *Neurological Sciences,* vol. 41, no. 12, 2020, pp. 3711–3717.

Margot-Cattin, Isabel, Nicolas Kuhne, Anders Kottorp, Malcolm Cutchin, Annika Öhman, and Louise Nygård. "Development of a Questionnaire to Evaluate Out-of-Home Participation for People with Dementia." *The American Journal of Occupational Therapy,* vol. 73, 2019, online only.

McKenzie, Karen, Dale Metcalfe, and George Murray. "A Review of Measures Used in the Screening, Assessment and Diagnosis of Dementia in People with an Intellectual Disability." *Journal of Applied Research in Intellectual Disabilities,* vol. 31, no. 5, 2018, pp. 725–742.

Miranda-Castillo, Claudia, Bob Woods, and Martin Orrell. "The Needs of People with Dementia Living at Home from User, Caregiver and Professional Perspectives: A Cross-Sectional Survey." *BMC Health Services Research,* vol. 13, no. 43, 2013, online only.

Overton, Eve, Paul S. Appelbaum, Stephanie R. Fisher, Daniel Dohan, Laura W. Roberts, and Laura B. Dunn. "Alternative Decision-Makers' Perspectives on Assent and Dissent for Dementia Research." *The American Journal of Geriatric Psychiatry,* vol. 21, no. 4, 2013, pp. 346–354.

Rakusa, Martin, Joze Jensterle, and Janez Mlakar. "Clock Drawing Test: A Simple Scoring System for the Accurate Screening of Cognitive Impairment in Patients with Mild Cognitive Impairment and Dementia." *Dementia and Geriatric Cognitive Disorders,* vol. 45, no. 5, 2018, pp. 326–334.

Robertson, Jane M. “Using Carer Biographical Narratives to Explore Factors Involved in Proxy Reporting of Quality of Life in People with Dementia.” *Aging & Mental Health,* vol. 21, no. 4, 2017, pp. 416–425.

Roydhouse, Jessica K., Roee Gutman, Nancy L. Keating, Vince Mor, and Ira B. Wilson. “Propensity Scores for Proxy Reports of Care Experience and Quality: Are They Useful?” *Health Services & Outcomes Research Methodology,* vol. 20, no. 1, 2020, pp. 40–59.

Seelye, Adriana, Nora Mattek, Nicole Sharma, Thomas Riley, Johanna Austin, Katherine Wild, Hiroko H. Dodge, Emily Lore, and Jeffrey Kaye. “Weekly Observations of Online Survey Metadata Obtained Through Home Computer Use Allow for Detection of Changes in Everyday Cognition Before Transition to Mild Cognitive Impairment.” *Alzheimer’s & Dementia,* vol. 14, no. 2, 2018, pp. 187–194.

Shepherd, Victoria, Kerenza Hood, Mark Sheehan, Richard Griffith, and Fiona Wood. “'It's a Tough Decision': A Qualitative Study of Proxy Decision-Making for Research Involving Adults Who Lack Capacity to Consent in UK.” *Age and Ageing,* vol. 48, no. 6, 2019, pp. 903–909.

Smith, S. C., A. A. J. Hendriks, S. J. Cano, and N. Black. “Proxy Reporting of Health-Related Quality of Life for People with Dementia: A Psychometric Solution.” *Health & Quality of Life Outcomes,* vol. 18, no. 1, 2020, pp. 1–10.

Takenoshita, S., S. Terada, R. Kuwano, T. Inoue, T. Kurozumi, A. Choju, S. Suemitsu, and N. Yamada. “Validation of the Japanese Version of the Dementia Screening Questionnaire for Individuals with Intellectual Disabilities.” *Journal of Intellectual Disability Research,* vol. 64, no. 12, 2020, pp. 970–979.

Tarzia, Laura, Michael Bauer, Deirdre Fetherstonhaugh, and Rhonda Nay. “Interviewing Older People in Residential Aged Care About Sexuality: Difficulties and Challenges.” *Sexuality and Disability*, vol. 31, no. 4, 2013, pp. 361–371.

Watchman, Karen, Kate Mattheys, Andrew Doyle, Louise Boustead, and Orlando Rincones. “Revisiting Photovoice: Perceptions of Dementia Among Researchers with Intellectual Disability.” *Qualitative Health Research,* vol. 30, no. 7, 2020, pp. 1019–1032.

c. Learning Disabilities

Bertills, Karin, Mats Granlund, and Lilly Augustine. “Measuring Self-Efficacy, Aptitude to Participate and Functioning in Students With and Without Impairments.” *European Journal of Special Needs Education,* vol. 33, no. 4, 2018, pp. 572–583.

Bunning, Karen, Ruth Alder, Lydia Proudman, and Harriet Wyborn. “Co-Production and Pilot of a Structured Interview Using Talking Mats® to Survey the Television Viewing Habits and Preferences of Adults and Young People with Learning Disabilities.” *British Journal of Learning Disabilities,* vol. 45, no. 1, 2017, pp. 1–11.

Chapko, Dorota, Pino Frumiento, Nalini Edwards, Lizzie Emeh, Donald Kennedy, David McNicholas, Michaela Overton, Mark Snead, Robyn Steward, Jenny M. Sutton, et al. "'We Have Been Magnified for Years - Now You Are Under the Microscope!': Co-Researchers with Learning Disabilities Created an Online Survey to Challenge Public Understanding of Learning Disabilities." *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems,* April 2020, pp. 1–17.

Goegan, Lauren D., Amanda I. Radil, and Lia M. Daniels. "Accessibility in Questionnaire Research: Integrating Universal Design to Increase the Participation of Individuals with Learning Disabilities." *Learning Disabilities,* vol. 16, no. 2, 2019, pp. 177–190.

Hart, Sarah M., Mikayla Pascucci, Sheetal Sood, and Emily M. Barrett. "Value, Vulnerability and Voice: An Integrative Review on Research Assent." *British Journal of Learning Disabilities,* vol. 48, no. 2, 2020, pp. 154–161.

Jahagirdar, Deepa, Thilo Kroll, Karen Ritchie, and Sally Wyke. "Patient-Reported Outcome Measures for Chronic Obstructive Pulmonary Disease: The Exclusion of People with Low Literacy Skills and Learning Disabilities." *The Patient,* vol. 6, no. 1, 2013, pp. 11–21.

Milner, Paul, and Patsie Frawley. "From 'on' to 'with' to 'by:' People with a Learning Disability Creating a Space for the Third Wave of Inclusive Research." *Qualitative Research,* vol. 19, no. 4, 2019, pp. 382–398.

Nind, Melanie, and Hilra Vinha. "Creative Interactions with Data: Using Visual and Metaphorical Devices in Repeated Focus Groups." *Qualitative Research,* vol. 16, no. 1, 2016, pp. 9–26.

O'Dwyer, John L., Amy M. Russell, Louise D. Bryant, Rebecca E.A. Walwyn, Alexandra M. Wright-Hughes, Elizabeth H. Graham, Judy M. Wright, Shaista Meer, Jacqueline Birtwistle, Amanda J. Farrin, Allan O. House, and Claire T. Hulme. "Developing and Feasibility Testing of Data Collection Methods for an Economic Evaluation of a Supported Selfmanagement Programme for Adults with a Learning Disability and Type 2 Diabetes." *BMC Pilot and Feasibility Studies,* vol. 4, no. 80, 2018, online only.

Owens, J., K. Jones, and Z. Marshman. "The Oral Health of People with Learning Disabilities - A User-Friendly Questionnaire Survey." *Community Dental Health*, vol. 34, no. 1, 2017, pp. 4–7.

Strnadová, Iva, Jan Walmsley, Kelley Johnson, and Therese M. Cumming. "Diverse Faces of Inclusive Research: Reflecting on Three Research Studies." *Scandinavian Journal of Disability Research,* vol. 18, no. 1, 2016, pp. 52–64.

d. Traumatic Brain Injury

Clarkson, Katrina, Lynne T. Stokes, Carol Sacchett, and Stephen Ashford. "Enabling People with Communication and Cognitive Impairments to Provide Feedback on Service Satisfaction: Development and Reliability Testing of an Adapted Pictorial Questionnaire." *International Journal of Therapy & Rehabilitation,* vol. 27, no. 7, 2020, pp. 1–15.

de Guise, Elaine, Sara Bélanger, Simon Tinawi, Kirsten Anderson, Joanne LeBlanc, Julie Lamoureux, Hé Audrit, and Mitra Feyz,. "Usefulness of the Rivermead Postconcussion Symptoms Questionnaire and the Trail-Making Test for Outcome Prediction in Patients with Mild Traumatic Brain Injury." *Applied Neuropsychology: Adult*, vol. 23, no. 3, 2016, pp. 213–222.

Formisano, Rita, Eloise Longo, Eva Azicnuda, Daniela Silvestro, Mariagrazia D'Ippolito, Jean-Luc Truelle, Lindsay Wilson, Jessica Rigon, Carmen Barba, Antonio Forcina, Marco Giustini, Nicole von Steinbüchel, and Klaus von Wild. "Quality of Life in Persons After Traumatic Brain Injury as Self-Perceived and as Perceived by the Caregivers." *Neurological Sciences,* vol. 38, no. 2, 2017, pp. 279–286.

Gardner, Raquel C., Ernesto Rivera, Megan O'Grady, Colin Doherty, Kristine Yaffe, John D. Corrigan, Jennifer Bogner, Joel Kramer, Fiona Wilson, Rudy Castellani, et al. "Screening for Lifetime History of Traumatic Brain Injury Among Older American and Irish Adults at Risk for Dementia: Development and Validation of a Web-Based Survey." *Journal of Alzheimer's Disease,* vol. 74, no. 2, 2020, pp. 699–711.

Lequerica, Anthony H., Nancy D. Chiaravalloti, Angelle M. Sander, Monique R. Pappadis, Juan C. Arango-Lasprilla, Tessa Hart, James H. Baños, Carlos Marquez De La Plata, Flora M. Hammond, and Tanya E. Sherman. "The Community Integration Questionnaire: Factor Structure Across Racial/Ethnic Groups in Persons with Traumatic Brain Injury." The *Journal of Head Trauma Rehabilitation*, vol. 28, no. 6, 2013, pp. E14–E22.

Lloyd, Owen, Tamara Ownsworth, Jennifer Fleming, and Melanie Zimmer-Gembeck. "Development and Preliminary Validation of the Paediatric Awareness Questionnaire for Children and Adolescents with Traumatic Brain Injury." *Child Neuropsychology,* vol. 24, no. 5, 2018, pp. 702–722.

Rietdijk, Rachael, Emma Power, Melissa Brunner, and Leanne Togher. "Reliability of Videoconferencing Administration of a Communication Questionnaire to People with Traumatic Brain Injury and Their Close Others." *The Journal of Head Trauma Rehabilitation,* vol. 32, no. 6, 2017, pp. E38–E44.

Sander, Angelle M., Allison N. Clark, Laura M. van Veldhoven, Robin Hanks, Tessa Hart, Luis L. Novelo, Esther Ngan, and David B. Arciniegas. "Factor Analysis of the Everyday Memory Questionnaire in Persons with Traumatic Brain Injury." *Clinical Neuropsychologist,* vol. 32, no. 3, 2018, pp. 495–509.

van den Broek, Martin D., Linda Monaci, and Jared G. Smith. "Personal Problems Questionnaire (PPQ): Normative Data and Utility in Assessing Acquired Neurological Impairment." *Archives of Clinical Neuropsychology,* vol. 34, no. 5, 2019, pp. 625–636.\

3. Sensory and Communication Impairments

Rix, Jonathan, Helena G. Carrizosa, Jane Seale, Kieron Sheehy, and Simon Hayhoe. "The While of Participation: A Systematic Review of Participatory Research Involving People with Sensory Impairments and/or Intellectual Impairments." *Disability & Society,* 2019, online ahead of print.

a. Blindness and Low Vision

Başçiftçi, Fatih, and Ayşe Eldem. "An Interactive and Multi-Functional Refreshable Braille Device for the Visually Impaired." *Displays,* vol. 41, 2016, pp. 33–41.

Davis, Bob. "Fielding Section 508 Compliant Web Surveys for Respondents with Disabilities." Presented at the American Association for Public Opinion Research conference, New Orleans, LA, May 2017.

Dim, Nem K., Kibum Kim, and Xiangshi Ren. "Designing Motion Marking Menus for People with Visual Impairments." *International Journal of Human-Computer Studies,* vol. 109, 2018, pp. 79–88.

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.

Fenwick, Eva K., Ryan E.K. Man, Gwyn Rees, Jill Keeffe, Tien Wong, Tien Y. Wong, and Ecosse L. Lamoureux. "Reducing Respondent Burden: Validation of the Brief Impact of Vision Impairment Questionnaire." *Quality of Life Research,* vol. 26, no. 2, 2017, pp. 479–488.

Finger, Robert P., Betty Tellis, Julie Crewe, Jill E. Keeffe, Lauren N. Ayton, and Robyn H. Guymer. "Developing the Impact of Vision Impairment–Very Low Vision (IVI-VLV) Questionnaire as Part of the LoVADA Protocol." *Investigative Ophthalmology & Visual Science,* vol. 55, no. 10, 2014, pp. 6150–6158.

Gleeson, Michael, Catherine Sherrington, Serigne Lo, Robin Auld, and Lisa Keay. "Impact of the Alexander Technique on Well-Being: A Randomised Controlled Trial Involving Older Adults with Visual Impairment." *Clinical and Experimental Optometry,* vol. 100, no. 6, 2017, pp. 633–641.

Green, Jane, Chloe Tolley, Sarah Bentley, Rob Arbuckle, Marie Burstedt, James Whelan, Karen Holopigian, Kali Stasi, Brigitte Sloesen, Claudio Spera, et al. "Qualitative Interviews to Better Understand the Patient Experience and Evaluate Patient-Reported Outcomes (PRO) in RLBP1 Retinitis Pigmentosa (RLBP1 RP)." *Advances in Therapy,* vol. 37, no. 6, 2020, pp. 2884–2901.

Iturregui-Gallardo, Gonzalo, and Jorge L. Méndez-Ulrich. "Towards the Creation of a Tactile Version of the Self-Assessment Manikin (T-SAM) for the Emotional Assessment of Visually Impaired People." *International Journal of Disability, Development and Education,* vol. 67, no. 6, 2020, pp. 657–674.

Jeter, Pamela E., Collin Rozanski, Robert Massof, Olukemi Adeyemo, and Gislin Dagnelie. "Development of the Ultra-Low Vision Visual Functioning Questionnaire (ULV-VFQ)." *Translational Vision Science & Technology,* vol. 6, no. 3, 2017, online only.

Labreche, Tammy, Krithika Nandakumar, Mohammed Althomali, and Susan J. Leat. "Development and Validation of Visual Impairment as a Risk for Falls Questionnaire." *Age and Ageing,* vol. 47, no. 3, 2018, pp. 444–450.

Marmeleira, José, Luís Laranjo, Olga Marques, and Nuno Batalha. "Criterion-Related Validity of the Short Form of the International Physical Activity Questionnaire in Adults Who Are Blind." *Journal of Visual Impairment & Blindness,* vol. 107, no. 5, 2013, pp. 375–381.

Packer, Jaclyn, and William Reuschel. "VoIP Accessibility: A Usability Study of Voice Over Internet Protocol (VoIP) Systems and a Survey of VoIP Users with Vision Loss." *Journal of Visual Impairment & Blindness,* vol. 112, no. 1, 2018, pp. 47–60.

Ramke, Jacqueline, Anna Palagyi, Hannah Kuper, and Clare E. Gilbert. "Assessment of Response Bias Is Neglected in Cross-Sectional Blindness Prevalence Surveys: A Review of Recent Surveys in Low- and Middle-Income Countries." *Ophthalmic Epidemiology,* vol. 25, no. 5, 2018, pp. 379–385.

b. Hearing Loss and Deafness

Amarasinghe, Akarshani, and Prasad Wimalaratne. "An Assistive Technology Framework for Communication with Hearing Impaired Persons." *GSTF Journal on Computing,* vol. 5, no. 2, 2018, pp. 1–7.

Bosch-Baliarda, Marta, Olga Soler Vilageliu, and Pilar Orero. "Toward a Sign Language-Friendly Questionnaire Design." *The Journal of Deaf Studies and Deaf Education,* vol. 24, no. 4, 2019, pp. 333–345.

Bozzay, Melanie L., Kimberly N. O'Leary, Alessandro S. De Nadai, Kim Gryglewicz, Gabriela Romero, and Marc S. Karver. "Adolescent Depression: Differential Symptom Presentations in Deaf and Hard-of-Hearing Youth Using the Patient Health Questionnaire-9." *Journal of Deaf Studies and Deaf Education,* vol. 22, no. 2, 2017, pp. 195–203.

Bright, Tess, and Danuk Pallawela. "Validated Smartphone-Based Apps for Ear and Hearing Assessments: A Review." *JMIR Rehabilitation and Assistive Technologies,* vol. 3, no. 2, 2016, online.

Broekhof, Evelien, Maartje Kouwenberg, Paul Oosterveld, Johan H. M. Frijns, and Carolien Rieffe. "Use of the Brief Shame and Guilt Questionnaire in Deaf and Hard of Hearing Children and Adolescents." *Assessment,* vol. 27, no. 1, 2020, pp. 194–205.

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 and Psychiatric Epidemiology.* Published ahead of print, September 14, 2020.

Heffernan, Eithne, David W. Maidment, Johanna G. Barry, and Melanie A. Ferguson. "Refinement and Validation of the Social Participation Restrictions Questionnaire: An Application of Rasch Analysis and Traditional Psychometric Analysis Techniques." *Ear and Hearing,* vol. 40, no. 2, 2019, pp. 328–339.

Heffernan, Eithne, Neil S. Coulson, and Melanie A. Ferguson. "Development of the Social Participation Restrictions Questionnaire (SPaRQ) Through Consultation with Adults with Hearing Loss, Researchers, and Clinicians: A Content Evaluation Study." *International Journal of Audiology,* vol. 57, no. 10, 2018, pp. 791–799.

Hoffman, Michael F., Ivette Cejas, and Alexandra L. Quittner. "Health-Related Quality of Life Instruments for Children with Cochlear Implants: Development of Child and Parent-Proxy Measures." *Ear and Hearing,* vol. 40, no. 3, 2019, pp. 592–604.

Hornsby, Benjamin W.Y., Samantha J. Gustafson, Hope Lancaster, Sun-Joo Cho, Stephen Camarata, and Fred H. Bess. "Subjective Fatigue in Children with Hearing Loss Assessed Using Self- and Parent-Proxy Report." *American Journal of Audiology,* vol. 26, 2017, pp. 393–407.

Kelly-Corless, Laura. "Delving in the Unknown: An Experience of Doing Research with d/Deaf Prisoners." *Qualitative Inquiry,* vol. 26, no. 3, 2020, pp. 355–368.

Kushalnagar, Poorna, Raychelle Harris, Raylene Paludneviciene, and TraciAnn Hoglind. "Health Information National Trends Survey in American Sign Language (HINTS-ASL): Protocol for the Cultural Adaptation and Linguistic Validation of a National Survey." *JMIR Research Protocols,* vol. 6, no. 9, 2017, online only.

Littlejohn, Jenna, Daniel Blackburn, and Annalena Venneri. "Understanding the Links between Hearing Impairment and Dementia: Development and Validation of the Social and Emotional Impact of Hearing Impairment (SEI-HI) Questionnaire." *Neurological Sciences,* vol. 41, no. 12, 2020, pp. 3711–3717.

Manchaiah, Vinaya, Sarah Granberg, Vibhu Grover, Gabrielle H. Saunders, and Deborah Ann Hall. "Content Validity and Readability of Patient-Reported Questionnaire Instruments of Hearing Disability." *International Journal of Audiology,* vol. 59, no. 9, 2019, pp. 565–575.

Menezes, Diogo, Luís Laranjo, and José Marmeleira. "Criterion-Related Validity of the Short Form of the International Physical Activity Questionnaire in Adults Who Are Deaf." *Disability and Health Journal,* vol. 10, no. 1, 2017, pp. 33–38.

Moreland, Christopher J., Darin Latimore, Ananda Sen, Nora Arato, and Philip Zazove. "Deafness Among Physicians and Trainees: A National Survey." *Academic Medicine,* vol. 88, no. 2, 2013, pp. 224–232.

Niemensivu, Riina, Risto P. Roine, Harri Sintonen, and Erna Kentala. "Health-Related Quality of Life in Hearing-Impaired Adolescents and Children." *Acta Oto-Laryngologica,* vol. 138, no. 7, 2018, pp. 652–658.

O'Brien, Dai. "Visual Research with Young d/Deaf People - An Investigation of the Transitional Experiences of d/Deaf Young People from Mainstream Schools Using Auto-Driven Photo-Elicitation Interviews." *Graduate Journal of Social Science,* vol. 10, no. 2, 2013, pp. 152–175.

Pardo-Guijarro, María J., Bencie Woll, Pablo Moya-Martínez, María Martínez-Andrés, Eugenio E. Cortés-Ramírez, and Vicente Martínez-Vizcaíno. "Validity and Reliability of the Spanish Sign Language Version of the KIDSCREEN-27 Health-Related Quality of Life Questionnaire for Use in Deaf Children and Adolescents." *Gaceta Sanitaria,* vol. 27, no. 4, 2013, pp. 318–324.

Singleton, Jenny L., Gabrielle Jones, and Shilpa Hanumantha. "Toward Ethical Research Practice with Deaf Participants." *Journal of Empirical Research on Human Research Ethics,* vol. 9, no. 3, 2014, pp. 59–66.

Wiley, Susan, and Jareen Meinzen-Derr. "Use of the Ages and Stages Questionnaire in Young Children Who Are Deaf/Hard of Hearing as a Screening for Additional Disabilities." *Early Human Development,* vol. 89, no. 5, 2013, pp. 295–300.

c. Autism Spectrum Disorder

Bellalou, Lucie, Naomi Downes, and Emilie Cappe. "Development and Preliminary Validation of a Depressive Symptomatology Detection Scale Among Children and Adolescents on the Autism Spectrum." *Autism*. Published ahead of print, September 21, 2020.

Bishop, Somer L., Marisela Huerta, Katherine Gotham, Karoline Alexandra Havdahl, Andrew Pickles, Amie Duncan, Vanessa Hus Bal, Lisa Croen, and Catherine Lord. "The Autism Symptom Interview, School-Age: A Brief Telephone Interview to Identify Autism Spectrum Disorders in 5-to-12-Year-Old Children." *Autism Research,* vol. 10, no. 1, 2017, pp. 78–88.

Fletcher-Watson, Sue, Kenneth Larsen, and Erica Salomone. "What Do Parents of Children with Autism Expect from Participation in Research? A Community Survey About Early Autism Studies." *Autism,* vol. 23, no. 1, 2019, pp. 175–186.

Gan, Shu-Mei, Li-Chen Tung, Chun-Yu Yeh, and Chun-Hou Wang. "ICF-CY Based Assessment Tool for Children with Autism." *Disability and Rehabilitation,* vol. 35, no. 8, 2013, pp. 678–685.

Gan, Shu-Mei, Li-Chen Tung, Chyong-Hwa Yeh, Hsiao-Yun Chang, and Chun-Hou Wang. "The ICF-CY-Based Structural Equation Model of Factors Associated with Participation in Children with Autism." *Developmental Neurorehabilitation,* vol. 17, no. 1, 2014, pp. 24–33.

Gómez, Laura E., M. L. Morán, M. Á. Alcedo, Víctor B. Arias, and Miguel-Ángel Verdugo. "Addressing Quality of Life of Children with Autism Spectrum Disorder and Intellectual Disability." *Intellectual & Developmental Disabilities,* vol. 58, no. 5, 2020, pp. 393–408.

Jafari, Parvin, Seyyed J. Younesi, Ali Asgary, and Mehdi Dastjerdi Kazemi. "Pragmatic Abilities in Children with Neurodevelopmental Disorders: Development of Pragmatic Abilities Questionnaire Based on the Rasch Rating Scale Model." *Psychology Research and Behavior Management,* vol. 12, 2019, pp. 629–639.

Knüppel, Ane, Gry K. Telléus, Helle Jakobsen, and Marlene B. Lauritsen. "Quality of Life in Adolescents and Adults with Autism Spectrum Disorder: Results from a Nationwide Danish Survey Using Self-Reports and Parental Proxy-Reports." *Research in Developmental Disabilities,* vol. 83, 2018, pp. 247–259.

Lipinski, Silke, Elisabeth S. Blanke, Ulrike Suenkel, and Isabel Dziobek. "Outpatient Psychotherapy for Adults with High-Functioning Autism Spectrum Condition: Utilization, Treatment Satisfaction, and Preferred Modifications." *Journal of Autism and Developmental Disorders,* vol. 49, 2019, pp. 1154–1168.

Maddox, Brenna B., Luc Lecavalier, Judith S. Miller, Jill Pritchett, Jill Hollway, Susan W. White, Scott Gillespie, Andrea N. Evans, Robert T. Schultz, John D. Herrington, et al. "Reliability and Validity of the Pediatric Anxiety Rating Scale Modified for Autism Spectrum Disorder." *Autism: The International Journal of Research & Practice,* vol. 24, no. 7, 2020, pp. 1773–1782.

Markowitz, Leslie A., Charina Reyes, Rebecca A. Embacher, Leslie L. Speer, Nancy Roizen, and Thomas W. Frazier. "Development and Psychometric Evaluation of a Psychosocial Quality-of-Life Questionnaire for Individuals with Autism and Related Developmental Disorders." *Autism,* vol. 20, no. 7, 2016, pp. 832–844.

Nicolaidis, Christina, Dora M. Raymaker, Katherine E. McDonald, Emily M. Lund, Sandra Leotti, Steven K. Kapp, Marsha Katz, Leanne M. Beers, Clarissa Kripke, Joelle Maslak, et al. "Creating Accessible Survey Instruments for use with Autistic Adults and People with Intellectual Disability: Lessons Learned and Recommendations." *Autism in Adulthood: Challenges and Management,* vol. 2, no. 1, 2020, pp. 61–76.

Nicolaidis, Christina, Dora Raymaker, Katherine McDonald, Sebastian Dern, W. Cody Boisclair, Elesia Ashkenazy, and Amanda Baggs. "Comparison of Healthcare Experiences in Autistic and Non-Autistic Adults: A Cross-Sectional Online Survey Facilitated by an Academic-Community Partnership." *Journal of General Internal Medicine,* vol. 28, no. 6, 2013, pp. 761–769.

d. Communication and Speech Impairments

Clarkson, Katrina, Lynne T. Stokes, Carol Sacchett, and Stephen Ashford. "Enabling People with Communication and Cognitive Impairments to Provide Feedback on Service Satisfaction: Development and Reliability Testing of an Adapted Pictorial Questionnaire." *International Journal of Therapy & Rehabilitation,* vol. 27, no. 7, 2020, pp. 1–15.

Davies, Katharine. "Conceptualizing Participation and Communication Disorder in Dementia Research." *Perspectives of the ASHA Special Interest Groups,* vol. 5, no. 1, 2020, pp. 256–260.

Dee-Price, Betty-Jean M., Lorna Hallahan, Diane Nelson Bryen, and Joanne M. Watson. "Every Voice Counts: Exploring Communication Accessible Research Methods." *Disability & Society,* February 18, 2020.

Eccles, Alicia, Reg Morris, and Ian Kneebone. "Psychometric Properties of the Behavioural Outcomes of Anxiety Questionnaire in Stroke Patients with Aphasia." *Clinical Rehabilitation,* vol. 31, no. 3, 2017, pp. 369–378.

Fernandes-Taylor, Sara, Cara Damico Smith, Natalia Arroyo, Kemberlee Bonnet, David Schlundt, Margarete Wichmann, Irene Feurer, and David O. Francis. "Study Protocol to Develop a Patient-Reported Outcome Measuring Disability Associated with Unilateral Vocal Fold Paralysis: A Mixed-Methods Approach with the CoPE Collaborative." *BMJ Open,* vol. 9, 2019, online only.

Hunting Pompon, Rebecca, Dagmar Amtmann, Charles Bombardier, and Diane Kendall. "Modifying and Validating a Measure of Chronic Stress for People with Aphasia." *Journal of Speech, Language, and Hearing Research,* vol. 61, no. 12, 2018, pp. 2934–2949.

Jayes, Mark J., and Rebecca L. Palmer. "Stroke Research Staff's Experiences of Seeking Consent from People with Communication Difficulties: Results of a National Online Survey." *Topics in Stroke Rehabilitation,* vol. 21, no. 5, 2014, pp. 443–451.

Nicholas, Marjorie, Lindsay Jennelle, Lisa T. Connor, Charles Haynes, and Lauryn Zipse. "Do Caregiver Proxy Reports and Congruence of Client-proxy Activity Participation Goals Relate to Quality of Life in People with Aphasia?" *International Journal of Language & Communication Disorders,* vol. 55, no. 3, 2020, pp. 373–386.

Paterson, Helen, and Christine Carpenter. "Using Different Methods to Communicate: How Adults with Severe Acquired Communication Difficulties Make Decisions About the Communication Methods They Use and How They Experience Them." *Disability and Rehabilitation,* vol. 37, no. 17, 2015, pp. 1522–1530.

Prior, Sarah, Andrea Miller, Steven Campbell, Karen Linegar, and Gregory Peterson. "The Challenges of Including Patients with Aphasia in Qualitative Research for Health Service Redesign: Qualitative Interview Study." *Journal of Participatory Medicine,* vol. 12, no. 1, 2020, article no. e12336.

Rand, Stacey, James Caiels, Grace Collins, and Julien Forder. "Developing a Proxy Version of the Adult Social Care Outcome Toolkit (ASCOT)." *BMC Health and Quality of Life Outcomes,* vol. 15, no. 108, 2017, online only.

Raven-Takken, Evelijn, Nicole Ter Wal, and Lizet Van Ewijk. "What Minimum Level of Language Comprehension Is Required for Reliable Administration of the SAQOL-39NLg?" *Aphasiology,* vol. 34, no. 6, 2020, pp. 674–687.

Rose, Tanya, Jessica Waterson, and Emma Caird. "The Communication Research Registry: Facilitating Access to Research Experiences for People with a Communication Disability." *Speech, Language and Hearing,* vol. 23, no. 4, 2020, pp. 208–220.

Soares, E. M., T. Granjo, S. Monteiro, S. Bemposta, and A. Salvador. "Accessible Communication in the Transport of Non-Urgent People with Communication Impairments." *European Journal of Public Health,* vol. 30, suppl. 2, 2020.

Trevisan, Filippo. "Making Focus Groups Accessible and Inclusive for People with Communication Disabilities: A Research Note." *Qualitative Research,* July 22, 2020.

Van Houtven, Courtney H., Steven J. Lippmann, Emmanuelle Belanger, Valerie A. Smith, Hailey J. James, Megan Shepherd-Banigan, Eric Jutkowitz, Emily O'Brien, Jennifer L. Wolff, James R. Burke, et al. "Measurement Properties of the CAPACITY Instrument to Assess Perceived Communication with the Health Care Team Among Care Partners of Patients with Cognitive Impairment." *Medical Care,* vol. 58, no. 9, 2020, pp. 842–849.

Verseghy, Judy, Lynda Atack, and Janet Maher. "Key Considerations When Interviewing Individuals with Expressive Language Difficulties." *Qualitative Research,* vol. 20, no. 6, 2020, pp. 960–970.

Wilson, Carlee, and Esther S. Kim. "Qualitative Data Collection: Considerations for People with Aphasia." *Aphasiology,* November 18, 2019.

4. Physical Impairments

a. Musculoskeletal Conditions

AlHeresh, Rawan, Michael P. LaValley, Wendy Coster, and Julie J. Keysor. "Construct Validity and Scoring Methods of the World Health Organization: Health and Work Performance Questionnaire Among Workers with Arthritis and Rheumatological Conditions." *Journal of Occupational and Environmental Medicine,* vol. 59, no. 6, 2017, pp. e112–e118.

Alvarez-Nebreda, M. Loreto, Marilyn Heng, Bernard Rosner, Michael McTague, Houman Javedan, Mitchel B. Harris, and Michael J. Weaver. "Reliability of Proxy-Reported Patient-Reported Outcomes Measurement Information System Physical Function and Pain Interference Responses for Elderly Patients with Musculoskeletal Injury." *The Journal of the American Academy of Orthopaedic Surgeons,* vol. 27, no. 4, 2019, pp. e156–e165.

Azevedo, Bruna R., Crystian B. Oliveira, Giulia M.D. Araujo, Fernanda G. Silva, Tatiana M. Damato, Rafael Z. Pinto, and Diego G.D. Christofaro. "Is There Equivalence Between the Electronic and Paper Version of the Questionnaires for Assessment of Patients with Chronic Low Back Pain?" *Spine,* 2018, online ahead of print.

Bailly, Florian, Violaine Foltz, Sylvie Rozenberg, Michael Norberg, Joelle Glemarec, Sophie Pouplin, Beatrice Banneville, Christophe Demoulin, Véronique Gaud-Listrat, Bruno Fautrel, and Laure Gossec. "Development and Validation of a Questionnaire Categorizing Behavioral Strategies in Patients with Chronic Low Back Pain." *Joint, Bone, Spine,* vol. 84, no. 6, 2017, pp. 725–731.

Bukhari, Marwan, and Alison Kent. "How Rheumatologists Assess Disability in the Current Era Needs an Overhaul: Focus on the Health Assessment Questionnaire." *Rheumatology,* vol. 59, no. 2, 2020, pp. 267–268.

Calmon Almeida, Verena, Walderi Monteiro da Silva Junior, Olaf K. de Camargo, Valter Joviniano de Santana Filho, Géssica U. Oliveira, Mylena S. Santana, and Jader Pereira de Farias Neto. "Do the Commonly Used Standard Questionnaires Measure What Is of Concern to Patients with Low Back Pain? " *Clinical Rehabilitation,* vol. 34, no. 10, 2020, pp. 1313–1324.

Carvalho, Flávia A., Priscila K. Morelhão, Marcia R. Franco, Chris G. Maher, Rob J.E.M. Smeets, Crystian B. Oliveira, Ismael F. Freitas Júnior, and Rafael Z. Pinto. "Reliability and Validity of Two Multidimensional Self-Reported Physical Activity Questionnaires in People with Chronic Low Back Pain." *Musculoskeletal Science and Practice,* vol. 27, 2017, pp. 65–70.

Chen, Ke-Yu, Mark Harniss, Shwetak Patel, and Kurt Johnson. "Implementing Technology-Based Embedded Assessment in the Home and Community Life of Individuals Aging with Disabilities: A Participatory Research and Development Study." *Disability and Rehabilitation: Assistive Technology,* vol. 9, no. 2, 2014, pp. 112–120.

Chiarotto, Alessandro, Carla Vanti, Christine Cedraschi, Silvano Ferrari, Fernanda de Lima e Sà Resende, Raymond W. Ostelo, and Paolo Pillastrini. "Responsiveness and Minimal Important Change of the Pain Self-Efficacy Questionnaire and Short Forms in Patients with Chronic Low Back Pain." *The Journal of Pain,* vol. 17, no. 6, 2016, pp. 707–718.

Chiarotto, Alessandro, Leo D. Roorda, Martine H. Crins, Maarten Boers, Raymond W. Ostelo, and Caroline B. Terwee. "PROMIS Physical Function Short Forms Display Item- and Scale-Level Characteristics at Least as Good as the Roland Morris Disability Questionnaire in Patients with Chronic Low Back Pain." *Archives of Physical Medicine and Rehabilitation,* 2019, online ahead of print.

Farin, Erik, Antje Ullrich, and Michaela Nagl. "Health Education Literacy in Patients with Chronic Musculoskeletal Diseases: Development of a New Questionnaire and Sociodemographic Predictors." *Health Education Research,* vol. 28, no. 6, 2013, pp. 1080–1091.

Farin, Erik, Michaela Nagl, and Antje Ullrich. "The Comprehensibility of Health Education Programs: Questionnaire Development and Results in Patients with Chronic Musculoskeletal Diseases." *Patient Education and Counseling,* vol. 90, no. 2, 2013, pp. 239–246.

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.

Hammond, Alison, Yeliz Prior, Mike C. Horton, Alan Tennant, and Sarah Tyson. "The Psychometric Properties of the Evaluation of Daily Activity Questionnaire in Seven Musculoskeletal Conditions." *Disability and Rehabilitation,* vol. 40, no. 17, 2018, pp. 2070–2080.

Honkavaara, Niklas, Amer N. Al-Ani, Pierre Campenfeldt, Wilhelmina Ekström, and Margareta Hedström. "Good Responsiveness with EuroQol 5-Dimension Questionnaire and Short Form (36) Health Survey in 20–69 Years Old Patients with a Femoral Neck Fracture: A 2-Year Prospective Follow-Up Study in 182 Patients." *Injury,* vol. 47, no. 8, 2016, pp. 1692–1697.

Iorio-Morin, Christian, Vanessa K. Noonan, Barry White, Luc Noreau, Jean Leblond, Frédéric S. Dumont, Brian K. Kwon, Marcel F. Dvorak, and Nicolas Dea. "Quality of Life and Health Utility Scores Among Canadians Living with Traumatic Spinal Cord Injury – A National Cross-Sectional Study." *Spine,* vol. 43, no. 14, 2018, pp. 999–1006.

Iwanaga, Kanako, John Blake, Rana Yaghmaian, Emre Umucu, Fong Chan, Jessica M. Brooks, Maryam Rahimi, and Timothy N. Tansey. "Preliminary Validation of a Short-Form Version of the Attachment Style Questionnaire for Use in Clinical Rehabilitation Counseling Research and Practice." *Rehabilitation Counseling Bulletin,* vol. 61, no. 4, 2018, pp. 205–216.

Katzan, Irene L., Nicolas R. Thompson, Steven Z. George, Sandi Passek, Frederick Frost, and Mary Stilphen. "The Use of STarT Back Screening Tool to Predict Functional Disability Outcomes in Patients Receiving Physical Therapy for Low Back Pain." *The Spine Journal,* vol. 19, no. 4, 2019, pp. 645–654.

Khan, Yasmeen, Dana Lawrence, Robert Vining, and Dustin Derby. "Measuring Biopsychosocial Risk for Back Pain Disability in Chiropractic Patients Using the STarT Back Screening Tool: A Cross-Sectional Survey." *Chiropractic & Manual Therapies,* vol. 27, no. 2, 2019, online only.

Kratz, A.L., C.Z. Kalpakjian, and R.A. Hanks. "Are Intensive Data Collection Methods in Pain Research Feasible in Those with Physical Disability? A Study in Persons with Chronic Pain and Spinal Cord Injury." *Quality of Life Research,* vol. 26, no. 3, 2017, pp. 587–600.

Kyrölä, Kati, Arja H. Häkkinen, Jari Ylinen, and Jussi P. Repo. "Further Validation of the Scoliosis Research Society (SRS-30) Questionnaire Among Adult Patients with Degenerative Spinal Disorder." *Disability and Rehabilitation,* 2019, online ahead of print.

Leahy, Edmund, Megan Davidson, Deenika Benjamin, and Henry Wajswelner. "Patient-Reported Outcome (PRO) Questionnaires for People with Pain in Any Spine Region. A Systematic Review." *Manual Therapy,* vol. 22, 2016, pp. 22–30.

Lee, Sharon S.S., Xiaohui Xin, Wan P. Lee, Eugene J. Sim, Benedict Tan, Michael P.G. Bien, Alexander S.T. Lau, and Julian Thumboo. "The Feasibility of Using SMS as a Health Survey Tool: An Exploratory Study in Patients with Rheumatoid Arthritis." *International Journal of Medical Informatics,* vol. 82, no. 5, 2013, pp. 427–434.

Nielsen, Anne M., Werner Vach, Peter Kent, Lise Hestbaek, and Alice Kongsted. "Using Existing Questionnaires in Latent Class Analysis: Should We Use Summary Scores or Single Items as Input? A Methodological Study Using a Cohort of Patients with Low Back Pain." *Clinical Epidemiology,* vol. 8, 2016, pp. 73–89.

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.

Pink, Joshua, Stavros Petrou, Esther Williamson, Mark Williams, and Sarah E. Lamb. "Properties of Patient-Reported Outcome Measures in Individuals Following Acute Whiplash Injury." *BMC Health and Quality of Life Outcomes,* vol. 12, no. 38, 2014, online only.

Şahinoğlu, Ertan, Gülbin Ergin, and Bayram Ünver. "Psychometric Properties of Patient-Reported Outcome Questionnaires for Patients with Musculoskeletal Disorders of the Shoulder." *Knee Surgery, Sports Traumatology, Arthroscopy,* vol. 27, no. 10, 2019, pp. 3188–3202.

Scott, Daniel J., J. Devin B. Watson, Thomas A. Heafner, Michael S. Clemens, Brandon W. Propper, and Zachary M. Arthurs. "Validation of the Short Musculoskeletal Function Assessment in Patients with Battlefield-Related Extremity Vascular Injuries." *Journal of Vascular Surgery,* vol. 60, no. 6, 2014, pp. 1620–1626.

Sleijser-Koehorst, Marije L.S., Lisette Bijker, Pim Cuijpers, Gwendolyne G.M. Scholten-Peeters, and Michel W. Coppieters. "Preferred Self-Administered Questionnaires to Assess Fear of Movement, Coping, Self-Efficacy, and Catastrophizing in Patients with Musculoskeletal Pain–A Modified Delphi Study." *Pain,* vol. 160, no. 3, 2019, pp. 600–606.

Stack, Rebecca J., Christian D. Mallen, Chris Deighton, Patrick Kiely, Karen L. Shaw, Alison Booth, Kanta Kumar, Susan Thomas, Ian Rowan, Rob Horne, Peter Nightingale, Sandy Herron-Marx, Clare Jinks, and Karim Raza. "The Development and Initial Validation of a Questionnaire to Measure Help-Seeking Behaviour in Patients with New Onset Rheumatoid Arthritis." *Health Expectations,* vol. 18, no. 6, 2015, pp. 2340–2355.

Stokes, Jonathan, Christopher J. Evans, Farrah Pompilus, Alan L. Shields, and Kent H. Summers. "Development of a Questionnaire to Assess the Impact of Chronic Low Back Pain for Use in Regulated Clinical Trials." *The Patient,* vol. 6, no. 4, 2013, pp. 291–305.

Vass, Caroline M., Niall J. Davison, Geert Vander Stichele, and Katherine Payne. "A Picture Is Worth a Thousand Words: The Role of Survey Training Materials in Stated-Preference Studies." *The Patient: Patient-Centered Outcomes Research,* vol. 13, no. 2, 2020, pp. 163–173.

Wager, J., F. Barth, L. Stahlschmidt, and B. Zernikow. "Testing the Validity of Telephone Interviews to Assess Chronic Pain in Children and Adolescents: A Randomized Cross-Over Trial." *European Journal of Pain,* vol.21, no. 10, 2017, pp. 1707–1716.

Wand, Benedict M., Mark J. Catley, Martin I. Rabey, Peter B. O'Sullivan, Neil E. O'Connell, and Anne J. Smith. "Disrupted Self-Perception in People with Chronic Low Back Pain. Further Evaluation of the Fremantle Back Awareness Questionnaire." *The Journal of Pain,* vol. 17, no. 9, 2016, pp. 1001–1012.

Weaver, Meaghann S., Rewais Hanna, Scott Hetzel, Karen Patterson, Alice Yuroff, Sarah Sund, Meredith Schultz, Mary Schroth, and Matthew A. Halanski. "A Prospective, Crossover Survey Study of Child- and Proxy-Reported Quality of Life According to Spinal Muscular Atrophy Type and Medical Interventions." *Journal of Child Neurology,* vol. 35, no. 5, 2020, pp. 322–330.

Williams, Toni L. "Exploring Narratives of Physical Activity and Disability Over Time: A Novel Integrated Qualitative Methods Approach." *Psychology of Sport and Exercise,* vol. 37, 2018, pp. 224–234.

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.

Ferro, Mark A., Shane W. Goodwin, Mark Sabaz, and Kathy N. Speechley. "Measurement Equivalence of the Newly Developed Quality of Life in Childhood Epilepsy Questionnaire (QOLCE-55)." *Epilepsia,* vol. 57, no. 3, 2016, pp. 427–435.

Henry, J.C. "Comment: Be Careful What You Ask When Interviewing Patients with Epilepsy." *Neurology,* vol. 85, no. 7, 2015, pp. 594.

Mirmosayyeb, Omid, Vahid Shaygannejad, and Mahsa Ghajarzadeh. "Comparison of Psychological Difficulties in Patients with Migraine and Epilepsy Using PARADISE-24 Questionnaire." *Journal of Multidisciplinary Healthcare,* vol. 13, 2020, pp. 609–613.

c. Muscular Dystrophy and Multiple Sclerosis

Beckmann, Helen, Matthias Augustin, Christoph Heesen, Jana Poettgen, and Christine Blome. "Benefit Evaluation in Multiple Sclerosis Relapse Treatment from the Patients' Perspective – Development and Validation of a New Questionnaire." *Multiple Sclerosis and Related Disorders,* vol. 28, 2019, pp. 256–261.

Campbell, Julie A., George A. Jelinek, Tracey J. Weiland, Nupur Nag, Sandra L. Neate, Andrew J. Palmer, Brendan Mulhern, Alysha De Livera, and Steve Simpson-Yap. "SF-6D Health State Utilities for Lifestyle, Sociodemographic and Clinical Characteristics of a Large International Cohort of People with Multiple Sclerosis." *Quality of Life Research: An International Journal of Quality of Life Aspects of Treatment, Care & Rehabilitation,* vol. 29, no. 9, 2020, pp. 2509–2527.

Chen, Ke-Yu, Mark Harniss, Shwetak Patel, and Kurt Johnson. "Implementing Technology-Based Embedded Assessment in the Home and Community Life of Individuals Aging with Disabilities: A Participatory Research and Development Study." *Disability and Rehabilitation: Assistive Technology,* vol. 9, no. 2, 2014, pp. 112–120.

Deroche, Chelsea B., Margaret M. Holland, Suzanne McDermott, Julie A. Royer, James W. Hardin, Joshua R. Mann, Deborah Salzberg, Orgul Ozturk, and Lijing Ouyang. "Development of a Tool to Describe Overall Health, Social Independence and Activity Limitation of Adolescents and Young Adults with Disability." *Research in Developmental Disabilities,* vol. 38, 2015, pp. 288–300.

Printza, A., M. Boziki, C. Bakirtzis, I. Nikolaidis, M. Kalaitzi, S. Triaridis, and N. Grigoriadis. "The Modified DYMUS Questionnaire Is a Reliable, Valid and Easy-to-Use Tool in the Assessment of Dysphagia in Multiple Sclerosis." *European Journal of Neurology,* vol. 27, no. 7, 2020, pp. 1231–1237.

Propp, Roni, Laura McAdam, Aileen M. Davis, Nancy M. Salbach, Shannon Weir, Clarissa Encisa, and Unni G. Narayanan. "Development and Content Validation of the Muscular Dystrophy Child Health Index of Life with Disabilities Questionnaire for Children with Duchenne Muscular Dystrophy." *Developmental Medicine & Child Neurology,* vol. 61, no. 1, 2019, pp. 75–81.

Skyrme, Sarah L., and Simon Woods. "Researching Disabled Children and Young People's Views on Decision-Making: Working Reflexively to Rethink Vulnerability." *Childhood,* vol. 25, no. 3, 2018, pp. 355–368.

Synnot, Anneliese, Sophie Hill, Michael Summers, and Michael Taylor. "Comparing Face-to-Face and Online Qualitative Research with People with Multiple Sclerosis." *Qualitative Health Research,* vol. 24, no. 3, 2014, pp. 431–438.

d. Other Physical Disabilities

Brogårdh, Christina, and Jan Lexell. "Test-Retest Reliability of the Self-Reported Impairments in Persons with Late Effects of Polio (SIPP) Rating Scale." *PM&R: The Journal of Injury, Function, and Rehabilitation,* vol. 8, no. 5, 2016, pp. 399–404.

D'Amico, Domenico, Licia Grazzi, Eleonora Grignani, Matilde Leonardi, Emanuela Sansone, Alberto Raggi, Venusia Covelli, Erika Guastafierro, Chiara Scaratti, Susanna Usai, et al. "HEADWORK Questionnaire: Why Do We Need a New Tool to Assess Work-Related Disability in Patients with Migraine?" *Headache: The Journal of Head & Face Pain,* vol. 60, no. 2, 2020, pp. 497–504.

Fernandes-Taylor, Sara, Cara Damico Smith, Natalia Arroyo, Kemberlee Bonnet, David Schlundt, Margarete Wichmann, Irene Feurer, and David O. Francis. "Study Protocol to Develop a Patient-Reported Outcome Measuring Disability Associated with Unilateral Vocal Fold Paralysis: A Mixed-Methods Approach with the CoPE Collaborative." *BMJ Open,* vol. 9, 2019, online only.

Fox, Rina S., John D. Peipert, Montserrat Vera-Llonch, Glenn Phillips, and David Cella. "PROMIS® and Neuro-QoL™ Measures Are Valid Measures of Health-Related Quality of Life Among Patients with Familial Chylomicronemia Syndrome." *Expert Review of Cardiovascular Therapy,* vol. 18, no. 4, 2020, pp. 231–238.

Györi, Eva, Christopher Przestrzelski, Igor Pona, Michael Hagmann, Thomas Rath, Christine Radtke, and C.-H. John Tzou. "Quality of Life and Functional Assessment of Facial Palsy Patients: A Questionnaire Study." *International Journal of Surgery,* vol. 55, 2018, pp. 92–97.

Ipsen, Catherine, Cathy Chambless, Noelle Kurth, Sara McCormick, Rebecca Goe, and Jean Hall. "Underrepresentation of Adolescents with Respiratory, Mental Health, and Developmental Disabilities Using American Community Survey (ACS) Questions." *Disability and Health Journal,* vol. 11, no. 3, 2018, pp. 447–450.

Jahagirdar, Deepa, Thilo Kroll, Karen Ritchie, and Sally Wyke. "Patient-Reported Outcome Measures for Chronic Obstructive Pulmonary Disease: The Exclusion of People with Low Literacy Skills and Learning Disabilities." *The Patient,* vol. 6, no. 1, 2013, pp. 11–21.

Jeannis, H., M. Goldberg, K. Seelman, M. Schmeler, and R. A. Cooper. "Participation in Science and Engineering Laboratories for Students with Physical Disabilities: Survey Development and Psychometrics." *Disability & Rehabilitation: Assistive Technology,* vol. 14, no. 7, 2019, pp. 692–709.

Kalpakjian, Claire Z., Jodi M. Kreschmer, Mary D. Slavin, Pamela A. Kisala, Elisabeth H. Quint, Nancy D. Chiaravalloti, Natalie Jenkins, Tamara Bushnik, Dagmar Amtmann, David S. Tulsky, et al. "Reproductive Health in Women with Physical Disability: A Conceptual Framework for the Development of New Patient-Reported Outcome Measures." *Journal of Women's Health,* vol. 29, no. 11, 2020, pp. 1427–1436.

Kanagasabai, Parimala S., Brigit Mirfin-Veitch, Leigh A. Hale, and Hilda Mulligan. "A Child-Centered Method of Interviewing Children with Movement Impairments." *Physical & Occupational Therapy in Pediatrics,* vol. 38, no. 3, 2018, pp. 255–268.

Kaur, Herminder, Paula Saukko, and Karen Lumsden. "Rhythms of Moving in and Between Digital Media: A Study on Video Diaries of Young People with Physical Disabilities." *Mobilities,* vol. 13, no. 3, 2018, pp. 397–410.

Kawata, Ariane K., Asha Hareendran, Shannon Shaffer, Sally Mannix, Andrew Thach, Pooja Desai, Daniel D. Mikol, Brian Ortmeier, Martha Bayliss, and Dawn C. Buse. "Evaluating the Psychometric Properties of the Migraine Functional Impact Questionnaire (MFIQ)." *Headache: The Journal of Head & Face Pain,* vol. 59, no. 8, 2019, pp. 1253–1269.

Ledger, Susan, Yu S. Bin, Monica Nour, Peter Cistulli, Adrian Bauman, Margaret Allman-Farinelli, Sharon L. Naismith, Emmanuel Stamatakis, Corinne Caillaud, Philip De Chazal, et al. "Internal Consistency and Convergent and Divergent Validity of the Liverpool Jetlag Questionnaire." *Chronobiology International: The Journal of Biological and Medical Rhythm Research,* vol. 37, no. 2, 2020, pp. 218–226.

Lima-Castro, Sandra, Vanessa Blanco, Patricia Otero, Lara López, and Fernando L. Vázquez. "Health-Related Quality of Life Among Persons with Physical Disabilities: A Systematic Review and Meta-Analysis." *Revista Iberoamericana De Psicología y Salud,* vol. 11, no. 2, 2020, pp. 82–102.

Marino, Molly E., Mark Meterko, Elizabeth E. Marfeo, Christine M. McDonough, Alan M. Jette, Pengsheng Ni, Kara Bogusz, Elizabeth K. Rasch, Diane E. Brandt, and Leighton Chan. "Work-Related Measures of Physical and Behavioral Health Function: Test-Retest Reliability." *Disability and Health Journal,* vol. 8, no. 4, 2015, pp. 652–657.

Minen, Mia T., Kaitlyn Morio, Kathryn B. Schaubhut, Scott W. Powers, Richard B. Lipton, and Elizabeth Seng. "Focus Group Findings on the Migraine Patient Experience During Research Studies and Ideas for Future Investigations." *Cephalalgia,* vol. 40, no. 7, 2020, pp. 712–734.

Mood, Laura, Dena Hassouneh, and Elizabeth McNeff. "A Conceptual Model to Promote the Retention of Women with Physical Disabilities in Research." *Public Health Nursing,* vol. 32, no. 4, 2015, pp. 368–377.

Morgan, Kerri A., Meghan Gottlieb, Holly H. Hollingsworth, and David B. Gray. "Work Environments of People with Mobility Impairments and Limitations: Mobility Device User Work Survey (MWS)." *Work,* vol. 48, no. 3, 2014, pp. 339–348.

O'Brien, Kelly K., Tarik Bereket, Marilyn Swinton, and Patricia Solomon. "Using Qualitative Methods to Assess the Measurement Property of a New HIV Disability Questionnaire." *International Journal of Qualitative Methods,* vol. 12, 2013, 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.

Pedersen, H., S. Söderström, and P.S. Kermit. "Assistive Activity Technology as Symbolic Expressions of the Self." *Technology and Disability,* vol. 31, no. 3, 2019, pp. 129–140.

Postma, S.A.E., K. van Boven, H. Ten Napel, D.L. Gerritsen, W.J.J. Assendelft, H. Schers, and T.C. olde Hartman. "The Development of an ICF-Based Questionnaire for Patients with Chronic Conditions in Primary Care." *Journal of Clinical Epidemiology,* vol. 103, 2018, pp. 92–100.

Raggi, Alberto, Venusia Covelli, Erika Guastafierro, Matilde Leonardi, Chiara Scaratti, Licia Grazzi, Marco Bartolini, Giovanna Viticchi, Sabina Cevoli, Giulia Pierangeli, Gioacchino Tedeschi, Antonio Russo, Piero Barbanti, Cinzia Aurilia, Carlo Lovati, Luca Giani, Fabio Frediani, Paola Di Fiore, Francesco Bono, Laura Rapisarda, and Domenico D'Amico. "Validation of a Self-Reported Instrument to Assess Work-Related Difficulties in Patients with Migraine: The HEADWORK Questionnaire." *The Journal of Headache and Pain,* vol. 19, no. 85, 2018, online only.

Sunnquist, Madison, Savitri Lazarus, and Leonard A. Jason. "The Development of a Short Form of the DePaul Symptom Questionnaire." *Rehabilitation Psychology,* vol. 64, no. 4, 2019, pp. 453–462.

Tompke, Braden K., Jennie Tang, Irina I. Oltean, M. C. Buchan, Shannon V. Reaume, and Mark A. Ferro. "Measurement Invariance of the WHODAS 2.0 Across Youth With and Without Physical or Mental Conditions." *Assessment,* vol. 27, no. 7, 2020, pp. 1490–1501.

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.

Walker, Lorraine O., Heather Becker, Erin E. Andrews, and Carolyn S. Phillips. "Adapting a Health Behavioral Change and Psychosocial Toolkit to the Context of Physical Disabilities: Lessons Learned from Disabled Women with Young Children." *Disability and Health Journal,* vol. 14, no. 1, 2021, online ahead of print.

Zur, Oz, and Eli Carmeli. "The University of California Los Angeles Dizziness Questionnaire: Advantages and Disadvantages." *Journal of Vestibular Research,* vol. 23, no. 6, 2013, pp. 279–283.

5. Psychiatric Impairments and Mental Health

Altman, Barbara M., Jennifer Madans, and Julie D. Weeks. "An Evaluation of the American Community Survey Indicators of Disability." *Disability and Health Journal,* vol. 10, no. 4, 2017, pp. 485–491.

Boström, Petra, Jakob Å. Johnels, Maria Thorson, and Malin Broberg. "Subjective Mental Health, Peer Relations, Family, and School Environment in Adolescents with Intellectual Developmental Disorder: A First Report of a New Questionnaire Administered on Tablet PCs." *Journal of Mental Health Research in Intellectual Disabilities,* vol. 9, no. 4, 2016, pp. 207–231.

Flynn, Samantha, Leen Vereenooghe, Richard P. Hastings, Dawn Adams, Sally-Ann Cooper, Nick Gore, Chris Hatton, Kerry Hood, Andrew Jahoda, Peter E. Langdon, Rachel McNamara, Chris Oliver, Ashok Roy, Vasiliki Totsika, and Jane Waite. "Measurement Tools for Mental Health Problems and Mental Well-Being in People with Severe or Profound Intellectual Disabilities: A Systematic Review." *Clinical Psychology Review,* vol. 57, 2017, pp. 32–44.

Hall, Charlotte L., Boliang Guo, Althea Z. Valentine, Madeline J. Groom, David Daley, Kapil Sayal, and Chris Hollis. "The Validity of the Strengths and Difficulties Questionnaire (SDQ) for Children with ADHD Symptoms." *PLoS ONE,* vol. 14, no. 6, 2019, online only.

Hall, Jean P., Catherine Ipsen, Noelle K. Kurth, Cathy Chambless, Sara McCormick, and Rebecca Goe. "Under-Representation of Certain Disability Groups by the American Community Survey (ACS)." *Disability and Health Journal,* vol. 10, no. 4, 2017, pp. 457–458.

Jafari, Parvin, Seyyed J. Younesi, Ali Asgary, and Mehdi Dastjerdi Kazemi. "Pragmatic Abilities in Children with Neurodevelopmental Disorders: Development of Pragmatic Abilities Questionnaire Based on the Rasch Rating Scale Model." *Psychology Research and Behavior Management,* vol. 12, 2019, pp. 629–639.

Kramer, Jessica M., Ariel E. Schwartz, Destiny Watkins, Micah Peace, Sara Luterman, Ben Barnhart, Jacob Bouma-Sims, Jessica Riley, Janet Shouse, Ravita Maharaj, Cordelia R. Rosenberg, Karyn Harvey, Juliana Huereña, Katy Schmid, and Jennifer S. Alexander. "Improving Research and Practice: Priorities for Young Adults with Intellectual/Developmental Disabilities and Mental Health Needs." *Journal of Mental Health Research in Intellectual Disabilities,* 2019, online ahead of print.

Marino, Molly E., Mark Meterko, Elizabeth E. Marfeo, Christine M. McDonough, Alan M. Jette, Pengsheng Ni, Kara Bogusz, Elizabeth K. Rasch, Diane E. Brandt, and Leighton Chan. "Work-Related Measures of Physical and Behavioral Health Function: Test-Retest Reliability." *Disability and Health Journal,* vol. 8, no. 4, 2015, pp. 652–657.

Michel, Jeremy J., Stephanie Mayne, Robert W. Grundmeier, James P. Guevara, Nathan J. Blum, Thomas J. Power, Emily Coffin, Jeffrey M. Miller, and Alexander G. Fiks. "Sharing of ADHD Information Between Parents and Teachers Using an EHR-Linked Application." *Applied Clinical Informatics,* vol. 9, no. 4, 2018, pp. 892–904.

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.

Scott, Haleigh M., and Susan M. Havercamp. "Comparison of Self- and Proxy Report of Mental Health Symptoms in People with Intellectual Disabilities." *Journal of Mental Health Research in Intellectual Disabilities,* vol. 11, no. 2, 2018, pp. 143–156.

Tompke, Braden K., Jennie Tang, Irina I. Oltean, M. C. Buchan, Shannon V. Reaume, and Mark A. Ferro. "Measurement Invariance of the WHODAS 2.0 Across Youth With and Without Physical or Mental Conditions." *Assessment,* vol. 27, no. 7, 2020, pp. 1490–1501.

a. Anxiety Disorders and Post-Traumatic Stress Disorder

Abraham, Traci H., Tisha L. Deen, Michelle Hamilton, Gala True, Marie T. O'Neil, Jessica Blanchard, and Madeline Uddo. "Analyzing Free-Text Survey Responses: An Accessible Strategy for Developing Patient-Centered Programs and Program Evaluation." *Evaluation and Program Planning,* vol. 78, 2020, online ahead of print.

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.

Boal, A.L., C.A. Vaughan, C.S. Sims, and J.N.V. Miles. "Measurement Invariance Across Administration Mode: Examining the Posttraumatic Stress Disorder (PTSD) Checklist." *Psychological Assessment,* vol. 29, no. 1, 2017, pp. 76–86.

Bovin, Michelle J., Shimrit K. Black, Paola Rodriguez, Carole A. Lunney, Sarah E. Kleiman, Frank W. Weathers, Paula P. Schnurr, James Spira, Terence M. Keane, and Brian P. Marx. "Development and Validation of a Measure of PTSD-Related Psychosocial Functional Impairment: The Inventory of Psychosocial Functioning." *Psychological Services,* vol. 15, no. 2, 2018, pp. 216–229.

Byllesby, Brianna M., Laura E. Stayton Coe, Benjamin D. Dickstein, and Kathleen M. Chard. "Psychometric Evaluation of the Brief Experiential Avoidance Questionnaire Among Treatment-Seeking Veterans with Posttraumatic Stress Disorder." *Psychological Trauma: Theory, Research, Practice, and Policy,* vol. 12, no. 7, 2020, pp. 785–789.

Clapp, Joshua D., Denise M. Sloan, William Unger, Daniel J. Lee, Janie J. Jun, Scott D. Litwack, and J.G. Beck. "Problematic Driving in Former Service Members: An Evaluation of the Driving Behavior Survey in Veterans with Posttraumatic Stress Disorder." *Journal of Anxiety Disorders,* vol. 67, 2019, online ahead of print.

Contractor, Ateka A., Nicole H. Weiss, Nathan T. Kearns, Stephanie V. Caldas, and Katherine L. Dixon-Gordon. "Assessment of Posttraumatic Stress Disorder's E2 Criterion: Development, Pilot Testing, and Validation of the Posttrauma Risky Behaviors Questionnaire." *International Journal of Stress Management,* vol. 27, no. 3, 2020, pp. 292–303.

Eccles, Alicia, Reg Morris, and Ian Kneebone. "Psychometric Properties of the Behavioural Outcomes of Anxiety Questionnaire in Stroke Patients with Aphasia." *Clinical Rehabilitation,* vol. 31, no. 3, 2017, pp. 369–378.

Geier, Timothy J., Joshua C. Hunt, Jessica L. Hanson, Katelyn Heyrman, Sadie E. Larsen, Karen J. Brasel, Terri A. deRoon-Cassini, and Terri deRoon-Cassini. "Validation of Abbreviated Four- and Eight-Item Versions of the PTSD Checklist for DSM-5 in a Traumatically Injured Sample." *Journal of Traumatic Stress,* vol. 33, no. 3, 2020, pp. 218–226.

Maddox, Brenna B., Luc Lecavalier, Judith S. Miller, Jill Pritchett, Jill Hollway, Susan W. White, Scott Gillespie, Andrea N. Evans, Robert T. Schultz, John D. Herrington, et al. "Reliability and Validity of the Pediatric Anxiety Rating Scale Modified for Autism Spectrum Disorder." *Autism: The International Journal of Research & Practice,* vol. 24, no. 7, 2020, pp. 1773–1782.

Mevissen, Liesbeth, Robert Didden, Ad de Jongh, and Hubert Korzilius. "Assessing Posttraumatic Stress Disorder in Adults with Mild Intellectual Disabilities or Borderline Intellectual Functioning." *Journal of Mental Health Research in Intellectual Disabilities,* vol. 13, no. 2, 2020, pp. 110–126.

Murphy, Dominic, Mark Shevlin, Emily Pearson, Neil Greenberg, Simon Wessely, Walter Busuttil, and Thanos Karatzias. "A Validation Study of the International Trauma Questionnaire to Assess Post-Traumatic Stress Disorder in Treatment-Seeking Veterans." *The British Journal of Psychiatry,* vol. 216, no. 3, 2020, pp. 132–137.

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.

Girard, V., A. Tinland, J.P. Bonin, F. Olive, J. Poule, C. Lancon, T. Apostolidis, M. Rowe, T. Greacen, and M.C. Simeoni. "Relevance of a Subjective Quality of Life Questionnaire for Long-Term Homeless Persons with Schizophrenia." *BMC Psychiatry,* vol. 17, no. 72, 2017, online only.

Ipsen, Catherine, Cathy Chambless, Noelle Kurth, Sara McCormick, Rebecca Goe, and Jean Hall. "Underrepresentation of Adolescents with Respiratory, Mental Health, and Developmental Disabilities Using American Community Survey (ACS) Questions." *Disability and Health Journal,* vol. 11, no. 3, 2018, pp. 447–450.

Michel, Pierre, Karine Baumstarck, Christophe Lancon, Badih Ghattas, Anderson Loundou, Pascal Auquier, and Laurent Boyer. "Modernizing Quality of Life Assessment: Development of a Multidimensional Computerized Adaptive Questionnaire for Patients with Schizophrenia." *Quality of Life Research,* vol. 27, no. 4, 2018, pp. 1041–1054.

Salzer, Mark S., Eugene Brusilovskiy, Janet Prvu-Bettger, and Petra Kottsieper. "Measuring Community Participation of Adults with Psychiatric Disabilities: Reliability of Two Modes of Data Collection." *Rehabilitation Psychology,* vol. 59, no. 2, 2014, pp. 211–219.

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

Abraham, Traci H., Tisha L. Deen, Michelle Hamilton, Gala True, Marie T. O'Neil, Jessica Blanchard, and Madeline Uddo. "Analyzing Free-Text Survey Responses: An Accessible Strategy for Developing Patient-Centered Programs and Program Evaluation." *Evaluation and Program Planning,* vol. 78, 2020, online ahead of print.

Bellalou, Lucie, Naomi Downes, and Emilie Cappe. "Development and Preliminary Validation of a Depressive Symptomatology Detection Scale Among Children and Adolescents on the Autism Spectrum." *Autism*. Published ahead of print, September 21, 2020.

Bozzay, Melanie L., Kimberly N. O'Leary, Alessandro S. De Nadai, Kim Gryglewicz, Gabriela Romero, and Marc S. Karver. "Adolescent Depression: Differential Symptom Presentations in Deaf and Hard-of-Hearing Youth Using the Patient Health Questionnaire-9." *Journal of Deaf Studies and Deaf Education,* vol. 22, no. 2, 2017, pp. 195–203.

Dang, Linh, Liming Dong, and Briana Mezuk. "Shades of Blue and Gray: A Comparison of the Center for Epidemiologic Studies Depression Scale and the Composite International Diagnostic Interview for Assessment of Depression Syndrome in Later Life." *Gerontologist,* vol. 60, no. 4, 2020, pp. e242–e253.

Gather, Jakov, Janice Kalagi, Ina Otte, and Georg Juckel. "Interviewing a Person with Bipolar Disorder Under Involuntary Commitment: A Case Report." *Journal of Empirical Research on Human Research Ethics,* vol. 14, no. 5, 2019, pp. 472–474.

Gleeson, Michael, Catherine Sherrington, Serigne Lo, Robin Auld, and Lisa Keay. "Impact of the Alexander Technique on Well-Being: A Randomised Controlled Trial Involving Older Adults with Visual Impairment." *Clinical & Experimental Optometry,* vol. 100, no. 6, 2017, pp. 633–641.

Gregersen, Merete, Mette M. Jordansen, and Debby L. Gerritsen. "Overall Quality of Life (OQoL) Questionnaire in Frail Elderly: A Study of Reproducibility and Responsiveness of the Depression List (DL)." *Archives of Gerontology and Geriatrics,* vol. 60, no. 1, 2015, pp. 22–27.

Guilera, Georgina, Juana Gómez-Benito, Óscar Pino, Emilio Rojo, Eduard Vieta, Manuel J. Cuesta, Scot E. Purdon, Miguel Bernardo, Benedicto Crespo-Facorro, Manuel Franco, Anabel Martínez-Arán, Gemma Safont, Rafael Tabarés-Seisdedos, and Javier Rejas. "Disability in Bipolar I Disorder: The 36-Item World Health Organization Disability Assessment Schedule 2.0." *Journal of Affective Disorders,* vol. 174, 2015, pp. 353–360.

Guillot-Valdés, María, Alejandro Guillén-Riquelme, and Gualberto Buela-Casal. "Reliability and Validity of the Basic Depression Questionnaire." *International Journal of Clinical and Health Psychology,* vol. 19, no. 3, 2019, pp. 243–250.

Ipsen, Catherine, Cathy Chambless, Noelle Kurth, Sara McCormick, Rebecca Goe, and Jean Hall. "Underrepresentation of Adolescents with Respiratory, Mental Health, and Developmental Disabilities Using American Community Survey (ACS) Questions." *Disability and Health Journal,* vol. 11, no. 3, 2018, pp. 447–450.

Lipinski, Silke, Elisabeth S. Blanke, Ulrike Suenkel, and Isabel Dziobek. "Outpatient Psychotherapy for Adults with High-Functioning Autism Spectrum Condition: Utilization, Treatment Satisfaction, and Preferred Modifications." *Journal of Autism and Developmental Disorders,* vol. 49, 2019, pp. 1154–1168.

Mileviciute, I., and S.L. Hartley. "Self-Reported Versus Informant-Reported Depressive Symptoms in Adults with Mild Intellectual Disability." *Journal of Intellectual Disability Research,* vol. 59, no. 2, 2015, pp. 158–169.

Salzer, Mark S., Eugene Brusilovskiy, Janet Prvu-Bettger, and Petra Kottsieper. "Measuring Community Participation of Adults with Psychiatric Disabilities: Reliability of Two Modes of Data Collection." *Rehabilitation Psychology,* vol. 59, no. 2, 2014, pp. 211–219.

B. Data Collection

1. Data Collection Mode and Adaptive Technologies

a. Interviewer-Administered Surveys

Adams, M. "Results and Their Implications from Comparing Respondents and Proxy Responses for Non-Respondents with Cognitive Difficulties on a Telephone Survey." *Disability and Health Journal,* vol. 10, no. 1, 2017, pp. 131–138.

Baker, Ashleigh T., Julie E. Byles, Deborah J. Loxton, Deirdre McLaughlin, Anna Graves, and Annette Dobson. "Utility and Acceptability of the Modified Telephone Interview for Cognitive Status in a Longitudinal Study of Australian Women Aged 85 to 90." *Journal of the American Geriatrics Society,* vol. 61, no. 7, 2013, pp. 1217–1220.

Bear, Todd, Howard Degenholtz, Jesse Evans, and Andrew Mrkva. "The Effects of a Pre-Notification Mailer on the Response, Productivity, and Costs Associated with a CATI Survey Among People Eligible for both Medicare and Medicaid." Presented at the American Association for Public Opinion Research conference, Denver, CO, May 2018.

Chandler, Jesse J. "Surveying Vocational Rehabilitation Applicants Online: A Feasibility Study." *Journal of Disability Policy Studies,* vol. 30, no. 3, 2019, pp. 164–173.

Eide, Arne H., Karin Dyrstad, Alister Munthali, Gert Van Rooy, Stine H. Braathen, Thomas Halvorsen, Frans Persendt, Peter Mvula, and Jan K. Rød. "Combining Survey Data, GIS and Qualitative Interviews in the Analysis of Health Service Access for Persons with Disabilities." *BMC International Health and Human Rights,* vol. 18, no. 26, 2018, online only.

Grau, Eric. "Do In-Person Interviews Reduce Bias in a Mixed-Mode Survey of Persons with Disabilities?" *Survey Practice,* vol. 7, no. 2, 2014, online only.

Johnson, Amy, Ryan Callahan, Jesse Chandler, and Jason Markesich. "Using Behavioral Science to Improve Survey Response: An Experiment with the National Beneficiary Survey." In Focus Brief. Washington, DC: Mathematica Policy Research, December 2017.

O'Dwyer, John L., Amy M. Russell, Louise D. Bryant, Rebecca E.A. Walwyn, Alexandra M. Wright-Hughes, Elizabeth H. Graham, Judy M. Wright, Shaista Meer, Jacqueline Birtwistle, Amanda J. Farrin, Allan O. House, and Claire T. Hulme. "Developing and Feasibility Testing of Data Collection Methods for an Economic Evaluation of a Supported Selfmanagement Programme for Adults with a Learning Disability and Type 2 Diabetes." *BMC Pilot and Feasibility Studies,* vol. 4, no. 80, 2018, online only.

Paterson, Helen, and Christine Carpenter. "Using Different Methods to Communicate: How Adults with Severe Acquired Communication Difficulties Make Decisions About the Communication Methods They Use and How They Experience Them." *Disability and Rehabilitation,* vol. 37, no. 17, 2015, pp. 1522–1530.

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.

Rand, Stacey, James Caiels, Grace Collins, and Julien Forder. “Developing a Proxy Version of the Adult Social Care Outcome Toolkit (ASCOT).” *BMC Health and Quality of Life Outcomes,* vol. 15, no. 108, 2017, online only.

Rietdijk, Rachael, Emma Power, Melissa Brunner, and Leanne Togher. “Reliability of Videoconferencing Administration of a Communication Questionnaire to People with Traumatic Brain Injury and Their Close Others.” *The Journal of Head Trauma Rehabilitation,* vol. 32, no. 6, 2017, pp. E38–E44.

Salzer, Mark S., Eugene Brusilovskiy, Janet Prvu-Bettger, and Petra Kottsieper. “Measuring Community Participation of Adults with Psychiatric Disabilities: Reliability of Two Modes of Data Collection.” *Rehabilitation Psychology,* vol. 59, no. 2, 2014, pp. 211–219.

Sola-Valls, Nuria, Helena Arino, Domingo Escudero, Elisabeth Solana, Albert Llado, Raquel Sanchez-Valle, Yolanda Blanco, Albert Saiz, Josep Dalmau, and Francesc Graus. “Telemedicine Assessment of Long-Term Cognitive and Functional Status in Anti-Leucine-Rich, Glioma-Inactivated 1 Encephalitis.” *Neurology Neuroimmunology & Neuroinflammation,* vol. 7, no. 2, 2020.

Synnot, Anneliese, Sophie Hill, Michael Summers, and Michael Taylor. “Comparing Face-to-Face and Online Qualitative Research with People with Multiple Sclerosis.” *Qualitative Health Research,* vol. 24, no. 3, 2014, pp. 431–438.

Wager, J., F. Barth, L. Stahlschmidt, and B. Zernikow. “Testing the Validity of Telephone Interviews to Assess Chronic Pain in Children and Adolescents: A Randomized Cross-Over Trial.” *European Journal of Pain,* vol. 21, no. 10, 2017, pp. 1707–1716.

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.

Azevedo, Bruna R., Crystian B. Oliveira, Giulia M.D. Araujo, Fernanda G. Silva, Tatiana M. Damato, Rafael Z. Pinto, and Diego G.D. Christofaro. “Is There Equivalence Between the Electronic and Paper Version of the Questionnaires for Assessment of Patients with Chronic Low Back Pain?” *Spine,* 2018, online ahead of print.

Chandler, Jesse J. “Surveying Vocational Rehabilitation Applicants Online: A Feasibility Study.” *Journal of Disability Policy Studies,* vol. 30, no. 3, 2019, pp. 164–173.

Chandler, Jesse. “Pilot Survey Using a Web-Based Follow Up Panel.” Presented at the State-of-the-Science Conference; Rehabilitation Research and Training Center on Disability Statistics and Demographics, Washington, DC, February 2017.

Cunha-Miranda, Luís, Helena Santos, Cláudia Miguel, Cândida Silva, Filipe Barcelos, Joana Borges, Ricardo Trinca, Vera Vicente, and Tiago Silva. "Validation of Portuguese-Translated Computer Touch-Screen Questionnaires in Patients with Rheumatoid Arthritis and Spondyloarthritis, Compared with Paper Formats." *Rheumatology International,* vol. 35, no. 12, 2015, pp. 2029–2035.

Davis, Bob. "Fielding Section 508 Compliant Web Surveys for Respondents with Disabilities." Presented at the American Association for Public Opinion Research conference, New Orleans, LA, May 2017.

De Cesarei, Andrea, and Bruno Baldaro. "Doing Online Research Involving University Students with Disabilities: Methodological Issues." *Computers in Human Behavior,* vol. 53, 2015, pp. 374–380.

Di Bari, Mauro, Francesco Profili, Stefania Bandinelli, Anna Salvioni, Enrico Mossello, Carla Corridori, Matilde Razzanelli, Teresa Di Fiandra, and Paolo Francesconi. "Screening for Frailty in Older Adults Using a Postal Questionnaire: Rationale, Methods, and Instruments Validation of the INTER-FRAIL Study." *Journal of the American Geriatrics Society,* vol. 62, no. 10, 2014, pp. 1933–1937.

Eide, Arne H., Karin Dyrstad, Alister Munthali, Gert Van Rooy, Stine H. Braathen, Thomas Halvorsen, Frans Persendt, Peter Mvula, and Jan K. Rød. "Combining Survey Data, GIS and Qualitative Interviews in the Analysis of Health Service Access for Persons with Disabilities." *BMC International Health and Human Rights,* vol. 18, no. 26, 2018, 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.

Ghandour, Reem M., Jessica R. Jones, Lydie A. Lebrun-Harris, Jessica Minnaert, Stephen J. Blumberg, Jason Fields, Christina Bethell, and Michael D. Kogan. "The Design and Implementation of the 2016 National Survey of Children's Health." *Maternal and Child Health Journal,* vol. 22, no. 8, 2018, pp. 1093–1102.

Gibson, Barbara E., Gillian King, Azadeh Kushki, Bhavnita Mistry, Laura Thompson, Gail Teachman, Beata Batorowicz, and Margot McMain-Klein. "A Multi-Method Approach to Studying Activity Setting Participation: Integrating Standardized Questionnaires, Qualitative Methods and Physiological Measures." *Disability and Rehabilitation,* vol. 36, no. 19, 2014, pp. 1652–1660.

Iturregui-Gallardo, Gonzalo, and Jorge L. Méndez-Ulrich. "Towards the Creation of a Tactile Version of the Self-Assessment Manikin (T-SAM) for the Emotional Assessment of Visually Impaired People." *International Journal of Disability, Development and Education,* vol. 67, no. 6, 2020, pp. 657–674.

Kovac, Martha, Stacie Feldman, Michael Levere, Jason Markesich and Karen CyBulski. "Offering a Web Mode for People with Disabilities: Descriptive Findings from the POD Follow Up Survey." Paper presented at the Eleventh Conference on Health Survey Research Methods, Williamsburg, VA, March 2020. Available at https://hsrmconference.com/sites/default/files/2020/presentations/1-3_Kovac.pdf.

Kushalnagar, Poorna, Raychelle Harris, Raylene Paludneviciene, and TraciAnn Hoglind. "Health Information National Trends Survey in American Sign Language (HINTS-ASL): Protocol for the Cultural Adaptation and Linguistic Validation of a National Survey." *JMIR Research Protocols,* vol. 6, no. 9, 2017, online only.

Livingston, Nicholas A., Tannis Hargrove, Lillie Greiman, Andrew Myers, Catherine Ipsen, and Craig Ravesloot. "An Investigation into the Temporal Scaling of Community Participation Measurement." *Rehabilitation Psychology,* vol. 60, no. 4, 2015, pp. 367–375.

Matulewicz, Holly, Karen Donelan, and Forest Crigler. "Challenges and Opportunities in Engaging Low-Income Populations with Disabilities in Web Surveys." Presented at the American Association for Public Opinion Research conference, New Orleans, LA, May 2017.

Michel, Pierre, Karine Baumstarck, Christophe Lancon, Badih Ghattas, Anderson Loundou, Pascal Auquier, and Laurent Boyer. "Modernizing Quality of Life Assessment: Development of a Multidimensional Computerized Adaptive Questionnaire for Patients with Schizophrenia." *Quality of Life Research,* vol. 27, no. 4, 2018, pp. 1041–1054.

Moreland, Christopher J., Darin Latimore, Ananda Sen, Nora Arato, and Philip Zazove. "Deafness Among Physicians and Trainees: A National Survey." *Academic Medicine,* vol. 88, no. 2, 2013, pp. 224–232.

Nicolaidis, Christina, Dora Raymaker, Marsha Katz, Mary Oschwald, Rebecca Goe, Sandra Leotti, Leah Grantham, Eddie Plourde, Janice Salomon, Rosemary B. Hughes, and Laurie E. Powers. "Community-Based Participatory Research to Adapt Health Measures for Use by People with Developmental Disabilities." *Progress in Community Health Partnerships: Research, Education, and Action,* vol. 9, no. 2, 2015, pp. 157–170.

O'Dwyer, John L., Amy M. Russell, Louise D. Bryant, Rebecca E.A. Walwyn, Alexandra M. Wright-Hughes, Elizabeth H. Graham, Judy M. Wright, Shaista Meer, Jacqueline Birtwistle, Amanda J. Farrin, Allan O. House, and Claire T. Hulme. "Developing and Feasibility Testing of Data Collection Methods for an Economic Evaluation of a Supported Selfmanagement Programme for Adults with a Learning Disability and Type 2 Diabetes." *BMC Pilot and Feasibility Studies,* vol. 4, no. 80, 2018, online only.

Oschwald, Mary, Sandy Leotti, Dora Raymaker, Marsha Katz, Rebecca Goe, Mark Harviston, Annie Wallington, Lisa Howard, Leanne Beers, Christina Nicolaidis, Susan Robinson-Whelen, Rosemary B. Hughes, Emily Lund, and Laurie E. Powers. "Development of an Audio-Computer Assisted Self-Interview to Investigate Violence and Health in the Lives of Adults with Developmental Disabilities." *Disability and Health Journal,* vol. 7, no. 3, 2014, pp. 292–301.

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.

Raley, Sheida K., Karrie A. Shogren, Graham G. Rifenbark, Mark H. Anderson, and Leslie A. Shaw. "Comparing the Impact of Online and Paper-and-Pencil Administration of the Self-Determination Inventory: Student Report." *Journal of Special Education Technology,* vol. 35, no. 3, 2020, pp. 133–144.

Rand, Stacey, James Caiels, Grace Collins, and Julien Forder. "Developing a Proxy Version of the Adult Social Care Outcome Toolkit (ASCOT)." *BMC Health and Quality of Life Outcomes,* vol. 15, no. 108, 2017, online only.

Salzer, Mark S., Eugene Brusilovskiy, Janet Prvu-Bettger, and Petra Kottsieper. "Measuring Community Participation of Adults with Psychiatric Disabilities: Reliability of Two Modes of Data Collection." *Rehabilitation Psychology,* vol. 59, no. 2, 2014, pp. 211–219.

Yang, Ming, Xiang Ding, and Birong Dong. "The Measurement of Disability in the Elderly: A Systematic Review of Self-Reported Questionnaires." *Journal of the American Medical Directors Association,* vol. 15, no. 2, 2014, pp. 150.e1–150.e9.

c. Ecological Momentary Assessments

Chen, Ke-Yu, Mark Harniss, Shwetak Patel, and Kurt Johnson. "Implementing Technology-Based Embedded Assessment in the Home and Community Life of Individuals Aging with Disabilities: A Participatory Research and Development Study." *Disability and Rehabilitation: Assistive Technology,* vol. 9, no. 2, 2014, pp. 112–120.

Gibson, Barbara E., Bhavnita Mistry, Brett Smith, Karen K. Yoshida, David Abbott, Sally Lindsay, and Yani Hamdani. "The Integrated Use of Audio Diaries, Photography, and Interviews in Research with Disabled Young Men." *International Journal of Qualitative Methods,* vol. 12, no. 1, 2013, pp. 382–402.

Kaur, Herminder, Paula Saukko, and Karen Lumsden. "Rhythms of Moving in and Between Digital Media: A Study on Video Diaries of Young People with Physical Disabilities." *Mobilities,* vol. 13, no. 3, 2018, pp. 397–410.

Kratz, A.L., C.Z. Kalpakjian, and R.A. Hanks. "Are Intensive Data Collection Methods in Pain Research Feasible in Those with Physical Disability? A Study in Persons with Chronic Pain and Spinal Cord Injury." *Quality of Life,* vol. 26, no. 3, 2017, pp. 587–600.

Livingston, Nicholas A., Tannis Hargrove, Lillie Greiman, Andrew Myers, Catherine Ipsen, and Craig Ravesloot. "An Investigation into the Temporal Scaling of Community Participation Measurement." *Rehabilitation Psychology,* vol. 60, no. 4, 2015, pp. 367–375.

McKeon, Ashlee, Michael McCue, Elizabeth Skidmore, Michelle Schein, and Jamie Kulzer. "Ecological Momentary Assessment for Rehabilitation of Chronic Illness and Disability." *Disability and Rehabilitation,* vol. 40, no. 8, 2018, pp. 974–987.

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.

Boström, Petra, Jakob Å. Johnels, Maria Thorson, and Malin Broberg. "Subjective Mental Health, Peer Relations, Family, and School Environment in Adolescents with Intellectual Developmental Disorder: A First Report of a New Questionnaire Administered on Tablet PCs." *Journal of Mental Health Research in Intellectual Disabilities,* vol. 9, no. 4, 2016, pp. 207–231.

Bright, Tess, and Danuk Pallawela. "Validated Smartphone-Based Apps for Ear and Hearing Assessments: A Review." *JMIR Rehabilitation and Assistive Technologies,* vol. 3, no. 2, 2016, online only.

Bunning, Karen, Ruth Alder, Lydia Proudman, and Harriet Wyborn. "Co-Production and Pilot of a Structured Interview Using Talking Mats® to Survey the Television Viewing Habits and Preferences of Adults and Young People with Learning Disabilities." *British Journal of Learning Disabilities,* vol. 45, no. 1, 2017, pp. 1-11.

Chandler, Jesse. "Pilot Survey Using a Web-Based Follow Up Panel." Presented at the State-of-the-Science Conference; Rehabilitation Research and Training Center on Disability Statistics and Demographics, Washington, DC, February 2017.

Chen, Ke-Yu, Mark Harniss, Shwetak Patel, and Kurt Johnson. "Implementing Technology-Based Embedded Assessment in the Home and Community Life of Individuals Aging with Disabilities: A Participatory Research and Development Study." *Disability and Rehabilitation: Assistive Technology,* vol. 9, no. 2, 2014, pp. 112–120.

Cihak, David F., Donald McMahon, Cate C. Smith, Rachel Wright, and Melinda M. Gibbons. "Teaching Individuals with Intellectual Disability to Email Across Multiple Device Platforms." *Research in Developmental Disabilities,* vol. 36, 2015, pp. 645–656.

Cunha-Miranda, Luís, Helena Santos, Cláudia Miguel, Cândida Silva, Filipe Barcelos, Joana Borges, Ricardo Trinca, Vera Vicente, and Tiago Silva. "Validation of Portuguese-Translated Computer Touch-Screen Questionnaires in Patients with Rheumatoid Arthritis and Spondyloarthritis, Compared with Paper Formats." *Rheumatology International,* vol. 35, no. 12, 2015, pp. 2029–2035.

Davis, Bob. "Fielding Section 508 Compliant Web Surveys for Respondents with Disabilities." Presented at the American Association for Public Opinion Research conference, New Orleans, LA, May 2017.

Dim, Nem K., Kibum Kim, and Xiangshi Ren. "Designing Motion Marking Menus for People with Visual Impairments." *International Journal of Human-Computer Studies,* vol. 109, 2018, pp. 79–88.

Doherty, Sean T., Patricia McKeever, Henna Aslam, Lindsay Stephens, and Nicole Yantzi. "Use of GPS Tracking to Interactively Explore Disabled Children's Mobility and Accessibility Patterns." *Children, Youth & Environments,* vol. 24, no. 1, 2014, pp. 1–24.

Koolhaas, Chantal M., Frank J. van Rooij, Magda Cepeda, Henning Tiemeier, Oscar H. Franco, and Josje D. Schoufour. "Physical Activity Derived from Questionnaires and Wrist-Worn Accelerometers: Comparability and the Role of Demographic, Lifestyle, and Health Factors Among a Population-Based Sample of Older Adults." *Clinical Epidemiology,* vol. 10, 2017, pp. 1–16.

Kovac, Martha, Stacie Feldman, Michael Levere, Jason Markesich and Karen CyBulski. "Offering a Web Mode for People with Disabilities: Descriptive Findings from the POD Follow Up Survey." Paper presented at the Eleventh Conference on Health Survey Research Methods, Williamsburg, VA, March 2020. Available at https://hsrmconference.com/sites/default/files/2020/presentations/1-3_Kovac.pdf.

Lee, Sharon S.S., Xiaohui Xin, Wan P. Lee, Eugene J. Sim, Benedict Tan, Michael P.G. Bien, Alexander S.T. Lau, and Julian Thumboo. "The Feasibility of Using SMS as a Health Survey Tool: An Exploratory Study in Patients with Rheumatoid Arthritis." *International Journal of Medical Informatics,* vol. 82, no. 5, 2013, pp. 427–434.

Makic, Mary B., Danielle Gilbert, Catherine Jankowski, Blaine Reeder, Nasser Al-Salmi, Whitney Starr, and Paul F. Cook. "Sensor and Survey Measures Associated with Daily Fatigue in HIV: Findings from a Mixed-Method Study." *JANAC: Journal of the Association of Nurses in AIDS Care,* vol. 31, no. 1, 2020, pp. 12–24.

Matulewicz, Holly, Karen Donelan, and Forest Crigler. "Challenges and Opportunities in Engaging Low-Income Populations with Disabilities in Web Surveys." Presented at the American Association for Public Opinion Research conference, New Orleans, LA, May 2017.

Menezes, Diogo, Luís Laranjo, and José Marmeleira. "Criterion-Related Validity of the Short Form of the International Physical Activity Questionnaire in Adults Who Are Deaf." *Disability and Health Journal,* vol. 10, no. 1, 2017, pp. 33–38.

Minen, Mia T., Kaitlyn Morio, Kathryn B. Schaubhut, Scott W. Powers, Richard B. Lipton, and Elizabeth Seng. "Focus Group Findings on the Migraine Patient Experience During Research Studies and Ideas for Future Investigations." *Cephalalgia,* vol. 40, no. 7, 2020, pp. 712–734.

Moss, Sarah J., and Stanislaw H. Czyz. "Level of Agreement Between Physical Activity Levels Measured by ActiHeart and the International Physical Activity Questionnaire in Persons with Intellectual Disability." *Disability and Rehabilitation,* vol. 40, no. 3, 2018, pp. 360–366.

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.

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, D., and A.I. Cuesta-Vargas. "Energy Expenditure Measured with Accelerometers and Self-Report Questionnaire in People with Intellectual Disabilities." *Journal of Intellectual Disability Research,* vol. 62, no. 8, 2018, pp. 701–708.

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.

Raghunath, Nisha, Jessamyn Dahmen, Katelyn Brown, Diane Cook, and Maureen Schmitter-Edgecombe. "Creating a Digital Memory Notebook Application for Individuals with Mild Cognitive Impairment to Support Everyday Functioning." *Disability and Rehabilitation: Assistive Technology,* 2019, online ahead of print.

Wilson, Nathan J., Yu-Wei Chen, Natasha Mahoney, Angus Buchanan, Anne Marks, and Reinie Cordier. "Experience Sampling Method and the Everyday Experiences of Adults with Intellectual Disability: A Feasibility Study." *Journal of Applied Research in Intellectual Disabilities,* vol. 33, no. 6, 2020, pp. 1328–1339.

e. Assistive Technologies

Amarasinghe, Akarshani, and Prasad Wimalaratne. "An Assistive Technology Framework for Communication with Hearing Impaired Persons." *GSTF Journal on Computing,* vol. 5, no. 2, 2017, pp. 1-7.

Başçiftçi, Fatih, and Ayşe Eldem. "An Interactive and Multi-Functional Refreshable Braille Device for the Visually Impaired." *Displays,* vol. 41, 2016, pp. 33–41.

Bunning, Karen, Ruth Alder, Lydia Proudman, and Harriet Wyborn. "Co-Production and Pilot of a Structured Interview Using Talking Mats® to Survey the Television Viewing Habits and Preferences of Adults and Young People with Learning Disabilities." *British Journal of Learning Disabilities,* vol. 45, no. 1, 2017, pp. 1-11.

Clarkson, Katrina, Lynne T. Stokes, Carol Sacchett, and Stephen Ashford. "Enabling People with Communication and Cognitive Impairments to Provide Feedback on Service Satisfaction: Development and Reliability Testing of an Adapted Pictorial Questionnaire." *International Journal of Therapy & Rehabilitation,* vol. 27, no. 7, 2020, pp. 1–15.

Dim, Nem K., Kibum Kim, and Xiangshi Ren. "Designing Motion Marking Menus for People with Visual Impairments." *International Journal of Human-Computer Studies,* vol. 109, 2018, pp. 79–88.

Kushalnagar, Poorna, Raychelle Harris, Raylene Paludneviciene, and TraciAnn Hoglind. "Health Information National Trends Survey in American Sign Language (HINTS-ASL): Protocol for the Cultural Adaptation and Linguistic Validation of a National Survey." *JMIR Research Protocols,* vol. 6, no. 9, 2017, online only.

Moreland, Christopher J., Darin Latimore, Ananda Sen, Nora Arato, and Philip Zazove. "Deafness Among Physicians and Trainees: A National Survey." *Academic Medicine,* vol. 88, no. 2, 2013, pp. 224–232.

Nicolaidis, Christina, Dora Raymaker, Marsha Katz, Mary Oschwald, Rebecca Goe, Sandra Leotti, Leah Grantham, Eddie Plourde, Janice Salomon, Rosemary B. Hughes, and Laurie E. Powers. "Community-Based Participatory Research to Adapt Health Measures for Use by People with Developmental Disabilities." *Progress in Community Health Partnerships: Research, Education, and Action,* vol. 9, no. 2, 2015, pp. 157–170.

O'Brien, Dai. "Visual Research with Young d/Deaf People - An Investigation of the Transitional Experiences of d/Deaf Young People from Mainstream Schools Using Auto-Driven Photo-Elicitation Interviews." *Graduate Journal of Social Science,* vol. 10, no. 2, 2013, pp. 152–175.

Oschwald, Mary, Sandy Leotti, Dora Raymaker, Marsha Katz, Rebecca Goe, Mark Harviston, Annie Wallington, Lisa Howard, Leanne Beers, Christina Nicolaidis, Susan Robinson-Whelen, Rosemary B. Hughes, Emily Lund, and Laurie E. Powers. "Development of an Audio-Computer Assisted Self-Interview to Investigate Violence and Health in the Lives of Adults with Developmental Disabilities." *Disability and Health Journal,* vol. 7, no. 3, 2014, pp. 292–301.

Packer, Jaclyn, and William Reuschel. "VoIP Accessibility: A Usability Study of Voice Over Internet Protocol (VoIP) Systems and a Survey of VoIP Users with Vision Loss." *Journal of Visual Impairment & Blindness,* vol. 112, no. 1, 2018, pp. 47–60.

Synnot, Anneliese, Sophie Hill, Michael Summers, and Michael Taylor. "Comparing Face-to-Face and Online Qualitative Research with People with Multiple Sclerosis." *Qualitative Health Research,* vol. 24, no. 3, 2014, pp. 431–438.

Timmins, Fiona, Pearl O'rourke, Annamaria Bagnasco, Bernard Timmins, Ray Ekins, Siobhan Long, Giuseppe Aleo, and Loredana Sasso. "Using Videoed Workshops in Interdisciplinary Research with People Who Have Disabilities." *Nurse Researcher,* vol. 25, no. 2, 2017, pp. 24–28.

2 Interviewing Techniques and Interviewer Effects

Bergmann, Michael, and Johanna Bristle. "Reading Fast, Reading Slow: The Effect of Interviewers' Speed in Reading Introductory Texts on Response Behavior." *Journal of Survey Statistics & Methodology,* vol. 8, no. 2, 2020, pp. 325–351.

Beullens, Koen, Geert Loosveldt, and Caroline Vandenplas. "Interviewer Effects Among Older Respondents in the European Social Survey." *International Journal of Public Opinion Research,* vol. 31, no. 4, 2019, pp. 609–625.

Callahan, Ryan. "Getting the Team Ready: Training and Certifying Interviewers for a Survey of People with Disabilities." Presented at the International Field Directors and Technology conference, Denver, CO, May 2018.

de Vries, Kay, Carol J. Leppa, Rosemarie Sandford, and Vasso Vydelingum. "Administering Questionnaires to Older People: Rigid Adherence to Protocol May Deny and Disacknowledge Emotional Expression." *Journal of Aging Studies,* vol. 31, 2014, pp. 132–138.

Digby, Robin, Susan Lee, and Allison Williams. "Interviewing People with Dementia in Hospital: Recommendations for Researchers." *Journal of Clinical Nursing,* vol. 25, no. 7-8, 2016, pp. 1156–1165.

Frielink, Noud, and Petri Embregts. "Modification of Motivational Interviewing for Use with People with Mild Intellectual Disability and Challenging Behaviour." *Journal of Intellectual & Developmental Disability,* vol. 38, no. 4, 2013, pp. 279–291.

Henry, J.C. "Comment: Be Careful What You Ask When Interviewing Patients with Epilepsy." *Neurology,* vol. 85, no. 7, 2015, pp. 594.

Hollomotz, Andrea. "Successful Interviews with People with Intellectual Disability." *Qualitative Research,* vol. 18, no. 2, 2018, pp. 153–170.

Kanagasabai, Parimala S., Brigit Mirfin-Veitch, Leigh A. Hale, and Hilda Mulligan. "A Child-Centered Method of Interviewing Children with Movement Impairments." *Physical & Occupational Therapy in Pediatrics,* vol. 38, no. 3, 2018, pp. 255–268.

Liew, Hui-Peng, and Sheena Gardner. "Exploring the Use of Paradata in Predicting Nonresponse in the Indonesian Family Life Survey." *Bulletin of Sociological Methodology,* vol. 126, no. 1, 2015, pp. 99–108.

O'Dwyer, John L., Amy M. Russell, Louise D. Bryant, Rebecca E.A. Walwyn, Alexandra M. Wright-Hughes, Elizabeth H. Graham, Judy M. Wright, Shaista Meer, Jacqueline Birtwistle, Amanda J. Farrin, Allan O. House, and Claire T. Hulme. "Developing and Feasibility Testing of Data Collection Methods for an Economic Evaluation of a Supported Selfmanagement Programme for Adults with a Learning Disability and Type 2 Diabetes." *BMC Pilot and Feasibility Studies,* vol. 4, no. 80, 2018, online only.

Verseghy, Judy, Lynda Atack, and Janet Maher. "Key Considerations When Interviewing Individuals with Expressive Language Difficulties." *Qualitative Research,* vol. 20, no. 6, 2020, pp. 960–970.

Wilson, Nathan J., Yu-Wei Chen, Natasha Mahoney, Angus Buchanan, Anne Marks, and Reinie Cordier. "Experience Sampling Method and the Everyday Experiences of Adults with Intellectual Disability: A Feasibility Study." *Journal of Applied Research in Intellectual Disabilities,* vol. 33, no. 6, 2020, pp. 1328–1339.

Wyman, Joshua D., Jennifer Lavoie, and Victoria Talwar. "Best Practices for Interviewing Children with Intellectual Disabilities in Maltreatment Cases." *Exceptionality,* vol. 27, no. 3, 2019, pp. 167–184.

3. Proxies

Adams, M. "Results and Their Implications from Comparing Respondents and Proxy Responses for Non-Respondents with Cognitive Difficulties on a Telephone Survey." *Disability and Health Journal,* vol. 10, no. 1, 2017, pp. 131–138.

Alvarez-Nebreda, M. Loreto, Marilyn Heng, Bernard Rosner, Michael McTague, Houman Javedan, Mitchel B. Harris, and Michael J. Weaver. "Reliability of Proxy-Reported Patient-Reported Outcomes Measurement Information System Physical Function and Pain Interference Responses for Elderly Patients with Musculoskeletal Injury." *The Journal of the American Academy of Orthopaedic Surgeons,* vol. 27, no. 4, 2019, pp. e156–e165.

Amspoker, Amber B., A. Lynn Snow, Brenna N. Renn, Phoebe Block, Sabrina Pickens, Robert O. Morgan, and Mark E. Kunik. "Patient Versus Informal Caregiver Proxy Reports of Pain Interference in Persons with Dementia." *Journal of Applied Gerontology.* Published ahead of print, February 6, 2020.

Arons, Alexander, Paul Krabbe, Gert Wilt, Marcel Olde Rikkert, and Eddy Adang. "Visual Analogue Scales: Scale Recalibration by Patients with Dementia and Their Proxies." *Quality of Life Research,* vol. 22, no. 5, 2013, pp. 979–986.

Barrios, Polaris, Ricardo González, Sherrie Hanna, Angela Lunde, Julie Fields, Dona Locke, and Glenn Smith. "Priority of Treatment Outcomes for Caregivers and Patients with Mild Cognitive Impairment: Preliminary Analyses." *Neurology and Therapy,* vol. 5, no. 2, 2016, pp. 183–192.

Bertelli, Marco O., Annamaria Bianco, Andrea Rossi, Michele Mancini, Giampaolo La Malfa, and Ivan Brown. "Impact of Severe Intellectual Disability on Proxy Instrumental Assessment of Quality of Life." *Journal of Intellectual & Developmental Disability,* vol. 44, no. 3, 2019, pp. 272–281.

Boström, Petra, Jakob Å. Johnels, Maria Thorson, and Malin Broberg. "Subjective Mental Health, Peer Relations, Family, and School Environment in Adolescents with Intellectual Developmental Disorder: A First Report of a New Questionnaire Administered on Tablet PCs." *Journal of Mental Health Research in Intellectual Disabilities,* vol. 9, no. 4, 2016, pp. 207–231.

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.

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.

Dada, Shakila, Anna K. Andersson, Adele May, Elisabeth E. Andersson, Mats Granlund, and Karina Huus. "Agreement Between Participation Ratings of Children with Intellectual Disabilities and Their Primary Caregivers." *Research in Developmental Disabilities,* vol. 104, 2020, article no. 103715.

Davis, Jennifer C., Ging-Yuek Hsiung, Stirling Bryan, Claudia Jacova, Patrizio Jacova, Michelle Munkacsy, Winnie Cheung, Philip Lee, and Teresa Liu-Ambrose. "Agreement Between Patient and Proxy Assessments of Quality of Life Among Older Adults with Vascular Cognitive Impairment Using the EQ-5D-3L and ICECAP-O." *PLoS ONE,* vol. 11, no. 4, 2016, online only.

de Geus-Neelen, Karin C.J.M., Wietske M.W.J. van Oorsouw, Lex A.H.C. Hendriks, and Petri J.C.M. Embregts. "Perceptions of Staff and Family of the Quality of Life of People with Severe to Profound Intellectual Disability." *Journal of Intellectual & Developmental Disability,* vol. 44, no. 1, 2019, pp. 42–50.

Emerson, Eric, David Felce, and Roger J. Stancliffe. "Issues Concerning Self-Report Data and Population-Based Data Sets Involving People with Intellectual Disabilities." *Intellectual & Developmental Disabilities,* vol. 51, no. 5, 2013, pp. 333–348.

Farina, Nicolas, Laura J. Hughes, Amber Watts, and Ruth G. Lowry. "Use of Physical Activity Questionnaires in People with Dementia: A Scoping Review." *Journal of Aging and Physical Activity,* 2018, pp. 1–24.

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 and Psychiatric Epidemiology.* Published ahead of print, September 14, 2020.

Formisano, Rita, Eloise Longo, Eva Azicnuda, Daniela Silvestro, Mariagrazia D'Ippolito, Jean-Luc Truelle, Lindsay Wilson, Jessica Rigon, Carmen Barba, Antonio Forcina, Marco Giustini, Nicole von Steinbüchel, and Klaus von Wild. "Quality of Life in Persons After Traumatic Brain Injury as Self-Perceived and as Perceived by the Caregivers." *Neurological Sciences,* vol. 38, no. 2, 2017, pp. 279–286.

Gomez-Gallego, M., J. Gomez-Garcia, and E. Ato-Lozano. "Addressing the Bias Problem in the Assessment of the Quality of Life of Patients with Dementia: Determinants of the Accuracy and Precision of the Proxy Ratings." *The Journal of Nutrition, Health & Aging,* vol. 19, no. 3, 2015, pp. 365–372.

Grau, Eric, and Jason Markesich. "Exploring Proxy Response Bias in a Large-Scale Survey of People with Disabilities." Paper presented at the Eleventh Conference on Health Survey Research Methods, Williamsburg, VA, March 2020.

Gruters, Angélique A.A., Inez H.G.B. Ramakers, Frans R.J. Verhey, Sebastian Köhler, Roy P.C. Kessels, Marjolein E. de Vugt, and Katherine Gifford. "Association Between Proxy- or Self-Reported Cognitive Decline and Cognitive Performance in Memory Clinic Visitors." *Journal of Alzheimer's Disease,* vol. 70, no. 4, 2019, pp. 1225–1239.

Hendriks, A.A. Jolijn, Sarah C. Smith, Theopisti Chrysanthaki, and Nick Black. "Reliability and Validity of a Self-Administration Version of DEMQOL-Proxy." *International Journal of Geriatric Psychiatry,* vol. 32, no. 7, 2017, pp. 734–741.

Hornsby, Benjamin W.Y., Samantha J. Gustafson, Hope Lancaster, Sun-Joo Cho, Stephen Camarata, and Fred H. Bess. "Subjective Fatigue in Children with Hearing Loss Assessed Using Self- and Parent-Proxy Report." *American Journal of Audiology,* vol. 26, 2017, pp. 393–407.

Jakobsson, Elin, Louise Nygård, Anders Kottorp, Cecilia B. Olsson, and Camilla Malinowsky. "The Use of Everyday Technology: A Comparison of Older Persons with Cognitive Impairments' Self-Reports and their Proxies' Reports." *British Journal of Occupational Therapy,* 2020.

Kelfve, Susanne, Mats Thorslund, and Carin Lennartsson. "Sampling and Non-Response Bias on Health-Outcomes in Surveys of the Oldest Old." *European Journal of Ageing,* vol. 10, no. 3, 2013, pp. 237–245.

Kelfve, Susanne. "Underestimated Health Inequalities Among Older People—A Consequence of Excluding the Most Disabled and Disadvantaged." *Journals of Gerontology Series B,* vol. 74, no. 8, 2019, pp. e125–e134.

Knüppel, Ane, Gry K. Telléus, Helle Jakobsen, and Marlene B. Lauritsen. "Quality of Life in Adolescents and Adults with Autism Spectrum Disorder: Results from a Nationwide Danish Survey Using Self-Reports and Parental Proxy-Reports." *Research in Developmental Disabilities,* vol. 83, 2018, pp. 247–259.

Kozlowski, Allan J., Ritika Singh, David Victorson, Ana Miskovic, Jin-Shei Lai, Richard L. Harvey, David Cella, and Allen W. Heinemann. "Agreement Between Responses from Community-Dwelling Persons with Stroke and Their Proxies on the NIH Neurological Quality of Life (Neuro-QoL) Short Forms." *Archives of Physical Medicine and Rehabilitation,* vol. 96, no. 11, 2015, pp. 1986–1992.

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.

Macháčová, Kateřina, Hana Vaňková, Iva Holmerová, Inna Čábelková, and Ladislav Volicer. "Ratings of Activities of Daily Living in Nursing Home Residents: Comparison of Self- and Proxy Ratings with Actual Performance and the Impact of Cognitive Status." *European Journal of Ageing,* vol. 15, no. 4, 2018, pp. 349–358.

Mileviciute, I., and S.L. Hartley. "Self-Reported Versus Informant-Reported Depressive Symptoms in Adults with Mild Intellectual Disability." *Journal of Intellectual Disability Research,* vol. 59, no. 2, 2015, pp. 158–169.

Miranda-Castillo, Claudia, Bob Woods, and Martin Orrell. "The Needs of People with Dementia Living at Home from User, Caregiver and Professional Perspectives: A Cross-Sectional Survey." *BMC Health Services Research,* vol. 13, no. 43, 2013, online only.

Moss, Sarah J., and Stanislaw H. Czyz. "Level of Agreement Between Physical Activity Levels Measured by ActiHeart and the International Physical Activity Questionnaire in Persons with Intellectual Disability." *Disability and Rehabilitation,* vol. 40, no. 3, 2018, pp. 360–366.

Nicholas, Marjorie, Lindsay Jennelle, Lisa T. Connor, Charles Haynes, and Lauryn Zipse. "Do Caregiver Proxy Reports and Congruence of Client-proxy Activity Participation Goals Relate to Quality of Life in People with Aphasia?" *International Journal of Language & Communication Disorders,* vol. 55, no. 3, 2020, pp. 373–386.

Nolan, Laura. "An Exploration of Proxy- and Self-Reported Adolescent Health in Low-Resource Settings." *Survey Research Methods,* vol. 10, no. 2, 2016, pp. 65–83.

Ottmann, Goetz, and Jenny Crosbie. "Mixed Method Approaches in Open-Ended, Qualitative, Exploratory Research Involving People with Intellectual Disabilities: A Comparative Methods Study." *Journal of Intellectual Disabilities,* vol. 17, no. 3, 2013, pp. 182–197.

Overton, Eve, Paul S. Appelbaum, Stephanie R. Fisher, Daniel Dohan, Laura W. Roberts, and Laura B. Dunn. "Alternative Decision-Makers' Perspectives on Assent and Dissent for Dementia Research." *The American Journal of Geriatric Psychiatry,* vol. 21, no. 4, 2013, pp. 346–354.

Roydhouse, Jessica K., Roee Gutman, Nancy L. Keating, Vince Mor, and Ira B. Wilson. "Propensity Scores for Proxy Reports of Care Experience and Quality: Are They Useful?" *Health Services & Outcomes Research Methodology,* vol. 20, no. 1, 2020, pp. 40–59.

Schützwohl, Matthias, Elke Voß, Hans J. Salize, Maja Stiawa, Bernd Puschner, and Andrea Koch. "Self- and Proxy-Rated Needs in Adults with Mild to Moderate Intellectual Disabilities: Perspective Matters." *Journal of Applied Research in Intellectual Disabilities,* vol. 31, no. 2, 2018, pp. 285–295.

Schwartz, Carolyn, Armon Ayandeh, Jonathan Rodgers, Paul Duberstein, Bianca Weinstock-Guttman, Ralph Benedict, Carolyn E. Schwartz, Jonathan D. Rodgers, and Ralph H. B. Benedict. "A New Perspective on Proxy Report: Investigating Implicit Processes of Understanding Through Patient-Proxy Congruence." *Quality of Life Research,* vol. 24, no. 11, 2015, pp. 2637–2649.

Scott, Haleigh M., and Susan M. Havercamp. "Comparison of Self- and Proxy Report of Mental Health Symptoms in People with Intellectual Disabilities." *Journal of Mental Health Research in Intellectual Disabilities,* vol. 11, no. 2, 2018, pp. 143–156.

Scott, Haleigh M., and Susan M. Havercamp. "Comparisons of Self and Proxy Report on Health-Related Factors in People with Intellectual Disability." *Journal of Applied Research in Intellectual Disabilities,* vol. 31, no. 5, 2018, pp. 927–936.

Sexton, Eithne, Mary-Ann O'Donovan, Niamh Mulryan, Philip McCallion, and Mary McCarron. "Whose Quality of Life? A Comparison of Measures of Self-Determination and Emotional Wellbeing in Research with Older Adults with and without Intellectual Disability." *Journal of Intellectual and Developmental Disability,* vol. 41, no. 4, 2016, pp. 324–337.

Shepherd, Victoria, Kerenza Hood, Mark Sheehan, Richard Griffith, and Fiona Wood. "'It's a Tough Decision': A Qualitative Study of Proxy Decision-Making for Research Involving Adults Who Lack Capacity to Consent in UK." *Age and Ageing,* vol. 48, no. 6, 2019, pp. 903–909.

Simões, Cristina, and Sofia Santos. "The Quality of Life Perceptions of People with Intellectual Disability and Their Proxies." *Journal of Intellectual & Developmental Disability,* vol. 41, no. 4, 2016, pp. 311–323.

Smith, S. C., A. A. J. Hendriks, S. J. Cano, and N. Black. "Proxy Reporting of Health-Related Quality of Life for People with Dementia: A Psychometric Solution." *Health & Quality of Life Outcomes,* vol. 18, no. 1, 2020, pp. 1–10.

Stancliffe, Roger J., Renáta Tichá, Sheryl A. Larson, Amy S. Hewitt, and Derek Nord. "Responsiveness to Self-Report Interview Questions by Adults with Intellectual and Developmental Disability." *Intellectual and Developmental Disabilities,* vol. 53, no. 3, 2015, pp. 163–181.

Stavrakantonaki, Marina, and Timothy P. Johnson. "Effects of Rosa's Law on Intellectual-Disability Reporting." *Public Opinion Quarterly,* vol. 82, no. 3, 2018, pp. 593–604.

Weaver, Meaghann S., Rewais Hanna, Scott Hetzel, Karen Patterson, Alice Yuroff, Sarah Sund, Meredith Schultz, Mary Schroth, and Matthew A. Halanski. "A Prospective, Crossover Survey Study of Child- and Proxy-Reported Quality of Life According to Spinal Muscular Atrophy Type and Medical Interventions." *Journal of Child Neurology,* vol. 35, no. 5, 2020, pp. 322–330.

4. Inclusive Strategies and Participatory Action Research

Arstein-Kerslake, Anna, Piers Gooding, Sarah Mercer, Marlena Raymond, and Bernadette McSherry. "Implementing a Participatory Human Rights-Based Research Methodology: The Unfitness to Plead Project." *Journal of Human Rights Practice,* vol. 11, no. 3, 2019, pp. 589–606.

Banas, Jennifer R., Susan Magasi, Kim The, and David E. Victorson. "Recruiting and Retaining People with Disabilities for Qualitative Health Research: Challenges and Solutions." *Qualitative Health Research,* vol. 29, no. 7, 2019, pp. 1056–1064.

Beail, Nigel, and Katie Williams. "Using Qualitative Methods in Research with People Who Have Intellectual Disabilities." *Journal of Applied Research in Intellectual Disabilities,* vol. 27, no. 2, 2014, pp. 85–96.

Bertills, Karin, Mats Granlund, and Lilly Augustine. "Measuring Self-Efficacy, Aptitude to Participate and Functioning in Students With and Without Impairments." *European Journal of Special Needs Education,* vol. 33, no. 4, 2018, pp. 572–583.

Bigby, Christine, Patsie Frawley, and Paul Ramcharan. "A Collaborative Group Method of Inclusive Research." *Journal of Applied Research in Intellectual Disabilities,* vol. 27, no. 1, 2014, pp. 54–64.

Blakeslee, Jennifer E., A. Del Quest, Jennifer Powers, Laurie E. Powers, Sarah Geenen, May Nelson, Lawrence D. Dalton, and Elizabeth McHugh. "Reaching Everyone: Promoting the Inclusion of Youth with Disabilities in Evaluating Foster Care Outcomes." *Children and Youth Services Review,* vol. 35, no. 11, 2013, pp. 1801–1808.

Brady, Geraldine, and Anita Franklin. "Challenging Dominant Notions of Participation and Protection Through a Co-Led Disabled Young Researcher Study." *Journal of Children's Services,* vol. 14, no. 3, 2019, pp. 174–185.

Chapko, Dorota, Pino Frumiento, Nalini Edwards, Lizzie Emeh, Donald Kennedy, David McNicholas, Michaela Overton, Mark Snead, Robyn Steward, Jenny M. Sutton, et al. "'We Have Been Magnified for Years - Now You Are Under the Microscope!': Co-Researchers with Learning Disabilities Created an Online Survey to Challenge Public Understanding of Learning Disabilities." *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems,* April 2020, pp. 1–17.

Clark, Lauren, Marjorie A. Pett, Elizabeth M. Cardell, Jia-Wen Guo, Erin Johnson, and Jia-Wen Guo. "Developing a Health-Related Quality-of-Life Measure for People with Intellectual Disability." *Intellectual and Developmental Disabilities,* vol. 55, no. 3, 2017, pp. 140–153.

Corby, Deirdre, and Mary R. Sweeney. "Researchers' Experiences and Lessons Learned from Doing Mixed-Methods Research with a Population with Intellectual Disabilities: Insights from the SOPHIE Study." *Journal of Intellectual Disabilities,* vol. 23, no. 2, 2019, pp. 250–265.

Cridland, Elizabeth K., Lyn Phillipson, Christopher Brennan-Horley, and Kate Swaffer. "Reflections and Recommendations for Conducting In-Depth Interviews with People with Dementia." *Qualitative Health Research,* vol. 26, no. 13, 2016, pp. 1774–1786.

Curtin, Carol, Linda G. Bandini, Aviva Must, Sarah Phillips, Melissa C.T. Maslin, Charmaine Lo, James M. Gleason, Richard K. Fleming, and Heidi I. Stanish. "Including Youth with Intellectual Disabilities in Health Promotion Research: Development and Reliability of a Structured Interview to Assess the Correlates of Physical Activity Among Youth." *Journal of Applied Research in Intellectual Disabilities,* vol. 29, no. 4, 2016, pp. 378–386.

Davis, Bob. "Fielding Section 508 Compliant Web Surveys for Respondents with Disabilities." Presented at the American Association for Public Opinion Research conference, New Orleans, LA, May 2017.

Di Lorito, Claudio, Alessandro Bosco, Linda Birt, and Angela Hassiotis. "Co-research with Adults with Intellectual Disability: A Systematic Review." *Journal of Applied Research in Intellectual Disabilities,* vol. 31, no. 5, 2018, pp. 669–686.

Digby, Robin, Susan Lee, and Allison Williams. "Interviewing People with Dementia in Hospital: Recommendations for Researchers." *Journal of Clinical Nursing,* vol. 25, no. 7-8, 2016, pp. 1156–1165.

Dorozenko, Kate P., Brian J. Bishop, and Lynne D. Roberts. "Fumblings and Faux Pas: Reflections on Attempting to Engage in Participatory Research with People with an Intellectual Disability." *Journal of Intellectual & Developmental Disability,* vol. 41, no. 3, 2016, pp. 197–208.

Fletcher-Watson, Sue, Kenneth Larsen, and Erica Salomone. "What Do Parents of Children with Autism Expect from Participation in Research? A Community Survey About Early Autism Studies." *Autism,* vol. 23, no. 1, 2019, pp. 175–186.

Frankena, T.K., J. Naaldenberg, M. Cardol, J.V. Meijering, G. Leusink, and H.M.J. van Schrojenstein Lantman-de Valk. "Exploring Academics' Views on Designs, Methods, Characteristics and Outcomes of Inclusive Health Research with People with Intellectual Disabilities: A Modified Delphi Study." *BMJ Open,* vol. 6, 2016, online only.

Frankena, Tessa K., Jenneken Naaldenberg, Hilde Tobi, Anneke van der Cruijsen, Henk Jansen, Henry van Schrojenstein Lantman - de Valk, Geraline Leusink, and Mieke Cardol. "A Membership Categorization Analysis of Roles, Activities and Relationships in Inclusive Research Conducted by Co-Researchers with Intellectual Disabilities." *Journal of Applied Research in Intellectual Disabilities,* vol. 32, no. 3, 2019, pp. 719–729.

Frankena, Tessa K., Jenneken Naaldenberg, Nienke Bekkema, Henny J.M. van Schrojenstein Lantman-de Valk, , Mieke Cardol, and Geraline Leusink. "An Exploration of the Participation of People with Intellectual Disabilities in Research – A Structured Interview Survey." *Journal of Applied Research in Intellectual Disabilities,* vol. 31, no. 5, 2018, pp. 942–947.

Georgiadou, Ioanna, Anastasia Vlachou, and Panayiota Stavroussi. "Development of the 'Special-Vocational-Education-Service-Quality Scale': Listening to the Voices of Students with Intellectual Disability." *Quality Assurance in Education: An International Perspective,* vol. 28, no. 2, 2020, pp. 89–103.

Goegan, Lauren D., Amanda I. Radil, and Lia M. Daniels. "Accessibility in Questionnaire Research: Integrating Universal Design to Increase the Participation of Individuals with Learning Disabilities." *Learning Disabilities,* vol. 16, no. 2, 2019, pp. 177–190.

Goujon, Nicolas, Alexandra Devine, Sally M. Baker, Beth Sprunt, Tanya J. Edmonds, Jennifer K. Booth, and Jill E. Keeffe. "A Comparative Review of Measurement Instruments to Inform and Evaluate Effectiveness of Disability Inclusive Development." *Disability and Rehabilitation,* vol. 36, no. 10, 2014, pp. 804–812.

Hall, Natalie, Marie-Anne Durand, and Silvana E. Mengoni. "'...their Opinions Mean Something': Care Staff's Attitudes to Health Research Involving People with Intellectual Disabilities." *British Journal of Learning Disabilities,* vol. 45, no. 3, 2017, pp. 198–207.

Heffron, Jenna L., Natasha A. Spassiani, Amber M. Angell, and Joy Hammel. "Using Photovoice as a Participatory Method to Identify and Strategize Community Participation with People with Intellectual and Developmental Disabilities." *Scandinavian Journal of Occupational Therapy,* vol. 25, no. 5, 2018, pp. 382–395.

Hollinrake, Sue, Sara Spencer, and Geof Dix. "Disabled Citizens as Researchers – Challenges and Benefits of Collaboration for Effective Action and Change." *European Journal of Social Work,* vol. 22, no. 5, 2019, pp. 749–762.

Jayes, Mark J., and Rebecca L. Palmer. "Stroke Research Staff's Experiences of Seeking Consent from People with Communication Difficulties: Results of a National Online Survey." *Topics in Stroke Rehabilitation,* vol. 21, no. 5, 2014, pp. 443–451.

Jen-Yi, Li, Malathy Krishnasamy, and Chen Der-Thanq. "Research with Persons with Intellectual Disabilities: An Inclusive Adaptation of Tourangeau's Model." *Alter,* vol. 9, no. 4, 2015, pp. 304–316.

Kaley, Alexandra, Chris Hatton, and Christine Milligan. "More than Words: The Use of Video in Ethnographic Research with People with Intellectual Disabilities." *Qualitative Health Research,* vol. 29, no. 7, 2019, pp. 931–943.

Kramer, Jessica M., and Ariel E. Schwartz. "Development of the Pediatric Disability Inventory-Patient Reported Outcome (PEDI-PRO) Measurement Conceptual Framework and Item Candidates." *Scandinavian Journal of Occupational Therapy,* vol. 25, no. 5, 2018, pp. 335–346.

Kramer, Jessica M., Ariel E. Schwartz, Destiny Watkins, Micah Peace, Sara Luterman, Ben Barnhart, Jacob Bouma-Sims, Jessica Riley, Janet Shouse, Ravita Maharaj, Cordelia R. Rosenberg, Karyn Harvey, Juliana Huereña, Katy Schmid, and Jennifer S. Alexander. "Improving Research and Practice: Priorities for Young Adults with Intellectual/Developmental Disabilities and Mental Health Needs." *Journal of Mental Health Research in Intellectual Disabilities,* 2019, online ahead of print.

Kramer, Jessica, Yishai Barth, Katie Curtis, Kit Livingston, Madeline O'Neil, Zach Smith, Samantha Vallier, and Ashley Wolfe. "Involving Youth with Disabilities in the Development and Evaluation of a New Advocacy Training: Project TEAM." *Disability and Rehabilitation,* vol. 35, no. 7, 2013, pp. 614–622.

Krol, M., H. Sixma, J. Meerdink, H. Wiersma, and J. Rademakers. "Exploring Young Patients' Perspectives on Rehabilitation Care: Methods and Challenges of Organizing Focus Groups for Children and Adolescents." *Child: Care, Health and Development,* vol. 40, no. 4, 2014, pp. 507–514.

Kushalnagar, Poorna, Raychelle Harris, Raylene Paludneviciene, and TraciAnn Hoglind. "Health Information National Trends Survey in American Sign Language (HINTS-ASL): Protocol for the Cultural Adaptation and Linguistic Validation of a National Survey." *JMIR Research Protocols,* vol. 6, no. 9, 2017, online only.

Liljenquist, Kendra, Jessica Kramer, Zachary Rossetti, and Wendy Coster. "Content Development, Accessibility and Feasibility of a Self-Report Tool for Use in Programmes Serving Youth with Cognitive Disabilities: The Participatory Experience Survey." *Australian Occupational Therapy Journal,* vol. 66, no. 4, 2019, pp. 490–499.

Lysaght, Rosemary, Rachelle Kranenburg, Carolyn Armstrong, and Terry Krupa. "Participant Recruitment for Studies on Disability and Work: Challenges and Solutions." *Journal of Occupational Rehabilitation,* vol. 26, no. 2, 2016, pp. 125–140.

Markesich, Jason A., Anne B. Ciemnecki, and Karen A. CyBulski. "Nothing About Them Without Them: Strategies for Including Hard-to-Reach People with Disabilities in Survey Research." Paper presented at the H2R International Conference on Methods for Surveying and Enumerating Hard-to-Reach Populations, New Orleans, LA, November 2012.

McDonald, Katherine E., and Erin Stack. "You Say You Want a Revolution: An Empirical Study of Community-Based Participatory Research with People with Developmental Disabilities." *Disability and Health Journal,* vol. 9, no. 2, 2016, pp. 201–207.

Milner, Paul, and Patsie Frawley. "From 'on' to 'with' to 'by:' People with a Learning Disability Creating a Space for the Third Wave of Inclusive Research." *Qualitative Research,* vol. 19, no. 4, 2019, pp. 382–398.

Morgan, Kerri A., Meghan Gottlieb, Holly H. Hollingsworth, and David B. Gray. "Work Environments of People with Mobility Impairments and Limitations: Mobility Device User Work Survey (MWS)." *Work,* vol. 48, no. 3, 2014, pp. 339–348.

Morgan, Michelle F., Karen B. Moni, and Monica Cuskelly. "The Development of Research Skills in Young Adults with Intellectual Disability in Participatory Research." *International Journal of Disability, Development and Education,* vol. 62, no. 4, 2015, pp. 438–457.

Morin, D., P. Valois, A.G. Crocker, and C. Robitaille. "Development and Psychometric Properties of the Attitudes Toward Intellectual Disability Questionnaire – Short Form." *Journal of Intellectual Disability Research,* vol. 63, no. 6, 2019, pp. 539–547.

Nicolaidis, Christina, Dora Raymaker, Katherine McDonald, Sebastian Dern, W. Cody Boisclair, Elesia Ashkenazy, and Amanda Baggs. "Comparison of Healthcare Experiences in Autistic and Non-Autistic Adults: A Cross-Sectional Online Survey Facilitated by an Academic-Community Partnership." *Journal of General Internal Medicine,* vol. 28, no. 6, 2013, pp. 761–769.

Nicolaidis, Christina, Dora Raymaker, Marsha Katz, Mary Oschwald, Rebecca Goe, Sandra Leotti, Leah Grantham, Eddie Plourde, Janice Salomon, Rosemary B. Hughes, and Laurie E. Powers. "Community-Based Participatory Research to Adapt Health Measures for Use by People with Developmental Disabilities." *Progress in Community Health Partnerships: Research, Education, and Action,* vol. 9, no. 2, 2015, pp. 157–170.

Nind, Melanie, and Hilra Vinha. "Creative Interactions with Data: Using Visual and Metaphorical Devices in Repeated Focus Groups." *Qualitative Research,* vol. 16, no. 1, 2016, pp. 9–26.

Northway, Ruth, Joyce Howarth, and Lynne Evans. "Participatory Research, People with Intellectual Disabilities and Ethical Approval: Making Reasonable Adjustments to Enable Participation." *Journal of Clinical Nursing,* vol. 24, no. 3-4, 2015, pp. 573–581.

O'Brien, Dai. "Visual Research with Young d/Deaf People - An Investigation of the Transitional Experiences of d/Deaf Young People from Mainstream Schools using Auto-Driven Photo-Elicitation Interviews." *Graduate Journal of Social Science,* vol. 10, no. 2, 2013, pp. 152–175.

O'Brien, Patricia, Roy McConkey, and Edurne García-Iriarte. "Co-Researching with People Who Have Intellectual Disabilities: Insights from a National Survey." *Journal of Applied Research in Intellectual Disabilities,* vol. 27, no. 1, 2014, pp. 65–75.

Oschwald, Mary, Sandy Leotti, Dora Raymaker, Marsha Katz, Rebecca Goe, Mark Harviston, Annie Wallington, Lisa Howard, Leanne Beers, Christina Nicolaidis, Susan Robinson-Whelen, Rosemary B. Hughes, Emily Lund, and Laurie E. Powers. "Development of an Audio-Computer Assisted Self-Interview to Investigate Violence and Health in the Lives of Adults with Developmental Disabilities." *Disability and Health Journal,* vol. 7, no. 3, 2014, pp. 292–301.

Overton, Eve, Paul S. Appelbaum, Stephanie R. Fisher, Daniel Dohan, Laura W. Roberts, and Laura B. Dunn. "Alternative Decision-Makers' Perspectives on Assent and Dissent for Dementia Research." *The American Journal of Geriatric Psychiatry,* vol. 21, no. 4, 2013, pp. 346–354.

Owens, J., K. Jones, and Z. Marshman. "The Oral Health of People with Learning Disabilities – A User-Friendly Questionnaire Survey." *Community Dental Health,* vol. 34, no. 1, 2017, pp. 4–7.

Paterson, Helen, and Christine Carpenter. "Using Different Methods to Communicate: How Adults with Severe Acquired Communication Difficulties Make Decisions About the Communication Methods They Use and How They Experience Them." *Disability and Rehabilitation,* vol. 37, no. 17, 2015, pp. 1522–1530.

Povee, Kate, Brian J. Bishop, and Lynne D. Roberts. "The Use of Photovoice with People with Intellectual Disabilities: Reflections, Challenges and Opportunities." *Disability & Society,* vol. 29, no. 6, 2014, pp. 893–907.

Prior, Sarah, Andrea Miller, Steven Campbell, Karen Linegar, and Gregory Peterson. "The Challenges of Including Patients with Aphasia in Qualitative Research for Health Service Redesign: Qualitative Interview Study." *Journal of Participatory Medicine,* vol. 12, no. 1, 2020, article no. e12336.

Purcal, Christiane, Karen R. Fisher, Sally Robinson, Ariella Meltzer, and Ngila Bevan. "Co-Production in Peer Support Group Research with Disabled People." *Area,* vol. 51, no. 3, 2019, pp. 405–414.

Puyalto, Carol, Maria Pallisera, Judit Fullana, and Montserrat Vilà. "Doing Research Together: A Study on the Views of Advisors with Intellectual Disabilities and Non-Disabled Researchers Collaborating in Research." *Journal of Applied Research in Intellectual Disabilities,* vol. 29, no. 2, 2016, pp. 146–159.

Riches, Tanya N., and Patricia M. O'Brien. "Can We Publish Inclusive Research Inclusively? Researchers with Intellectual Disabilities Interview Authors of Inclusive Studies." *British Journal of Learning Disabilities,* vol. 48, no. 4, 2020, pp. 272–280.

Rix, Jonathan, Helena G. Carrizosa, Jane Seale, Kieron Sheehy, and Simon Hayhoe. "The While of Participation: A Systematic Review of Participatory Research Involving People with Sensory Impairments and/or Intellectual Impairments." *Disability & Society,* 2019, online ahead of print.

Rose, Tanya, Jessica Waterson, and Emma Caird. "The Communication Research Registry: Facilitating Access to Research Experiences for People with a Communication Disability." *Speech, Language and Hearing,* vol. 23, no. 4, 2020, pp. 208–220.

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.

Schwartz, Ariel E., and Brendan Durkin. "'Team is Everything': Reflections on Trust, Logistics and Methodological Choices in Collaborative Interviewing" *British Journal of Learning Disabilities,* vol. 48, no. 2, 2020, pp. 115–123.

Schwartz, Ariel E., and Jessica M. Kramer. "Inclusive Approaches to Developing Content Valid Patient-Reported Outcome Measure Response Scales for Youth with Intellectual/Developmental Disabilities." *British Journal of Learning Disabilities.* Published ahead of print, October 6, 2020.

Schwartz, Ariel E., Jessica M. Kramer, Ellen S. Cohn, and Katherine E. McDonald. “‘That Felt Like Real Engagement': Fostering and Maintaining Inclusive Research Collaborations with Individuals with Intellectual Disability” *Qualitative Health Research,* vol. 30, no. 2, 2020, pp. 236–249.

Singleton, Jenny L., Gabrielle Jones, and Shilpa Hanumantha. “Toward Ethical Research Practice with Deaf Participants.” *Journal of Empirical Research on Human Research Ethics,* vol. 9, no. 3, 2014, pp. 59–66.

Sitter, Kathleen C. “Participatory Video Analysis in Disability Research.” *Disability & Society,* vol. 30, no. 6, 2015, pp. 910–923.

Skyrme, Sarah L., and Simon Woods. “Researching Disabled Children and Young People’s Views on Decision-Making: Working Reflexively to Rethink Vulnerability.” *Childhood,* vol. 25, no. 3, 2018, pp. 355–368.

St. John, Brittany, Iulia Mihaila, Katelyn Dorrance, Leann S. DaWalt, and Karla K. Ausderau. “Reflections from Co-Researchers with Intellectual Disability: Benefits to Inclusion in a Research Study Team.” *Intellectual and Developmental Disabilities,* vol. 56, no. 4, 2018, pp. 251–262.

Stack, Erin E., and Katherine McDonald. “We Are ‘Both in Charge, the Academics and Self-Advocates’: Empowerment in Community-Based Participatory Research.” *Journal of Policy and Practice in Intellectual Disabilities,* vol. 15, no. 1, 2018, pp. 80–89.

Stack, Rebecca J., Christian D. Mallen, Chris Deighton, Patrick Kiely, Karen L. Shaw, Alison Booth, Kanta Kumar, Susan Thomas, Ian Rowan, Rob Horne, Peter Nightingale, Sandy Herron-Marx, Clare Jinks, and Karim Raza. “The Development and Initial Validation of a Questionnaire to Measure Help-Seeking Behaviour in Patients with New Onset Rheumatoid Arthritis.” *Health Expectations,* vol. 18, no. 6, 2015, pp. 2340–2355.

Stevenson, Miriam. “Participatory Data Analysis Alongside Co-Researchers Who Have Down Syndrome.” *Journal of Applied Research in Intellectual Disabilities,* vol. 27, no. 1, 2014, pp. 23–33.

Strnadová, Iva, and Jan Walmsley. “Peer-Reviewed Articles on Inclusive Research: Do Co-Researchers with Intellectual Disabilities Have a Voice?” *Journal of Applied Research in Intellectual Disabilities,* vol. 31, no. 1, 2018, pp. 132–141.

Strnadová, Iva, Jan Walmsley, Kelley Johnson, and Therese M. Cumming. “Diverse Faces of Inclusive Research: Reflecting on Three Research Studies.” *Scandinavian Journal of Disability Research,* vol. 18, no. 1, 2016, pp. 52–64.

Strnadová, Iva, Therese M. Cumming, Marie Knox, and Trevor Parmenter. “Building an Inclusive Research Team: The Importance of Team Building and Skills Training.” *Journal of Applied Research in Intellectual Disabilities,* vol. 27, no. 1, 2014, pp. 13–22.

Synnot, Anneliese, Sophie Hill, Michael Summers, and Michael Taylor. “Comparing Face-to-Face and Online Qualitative Research with People with Multiple Sclerosis.” *Qualitative Health Research,* vol. 24, no. 3, 2014, pp. 431–438.

Turnpenny, Agnes, James Caiels, Beckie Whelton, Lisa Richardson, Julie Beadle-Brown, Tanya Crowther, Julien Forder, Joanna Apps, and Stacey Rand. "Developing an Easy Read Version of the Adult Social Care Outcomes Toolkit (ASCOT)." *Journal of Applied Research in Intellectual Disabilities,* vol. 31, no. 1, 2018, pp. e36–e48.

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,* 2019.

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

Walker, Lorraine O., Heather Becker, Erin E. Andrews, and Carolyn S. Phillips. "Adapting a Health Behavioral Change and Psychosocial Toolkit to the Context of Physical Disabilities: Lessons Learned from Disabled Women with Young Children." *Disability and Health Journal,* vol. 14, no. 1, 2021, online ahead of print.

Walmsley, Jan, Iva Strnadová, and Kelley Johnson. "The Added Value of Inclusive Research." *Journal of Applied Research in Intellectual Disabilities,* vol. 31, no. 5, 2018, pp. 751–759.

Watchman, Karen, Kate Mattheys, Andrew Doyle, Louise Boustead, and Orlando Rincones. "Revisiting Photovoice: Perceptions of Dementia Among Researchers with Intellectual Disability." *Qualitative Health Research,* vol. 30, no. 7, 2020, pp. 1019–1032.

Wickenden, Mary, and Gayatri Kembhavi-Tam. "Ask Us too! Doing Participatory Research with Disabled Children in the Global South." *Childhood,* vol. 21, no. 3, 2014, pp. 400–417.

Wright-Bevans, Katie, Michael Richards, Mary Brydon-Miller, Michael Kral, and Alfredo Ortiz Aragón. "Using PAR to Promote Social Justice for Older People and People with Intellectual Disabilities." *International Review of Qualitative Research,* vol. 13, no. 2, 2020, pp. 219–232.

5. Qualitative Methods

Bakker-van Gijssel, Esther J., Peter L.B.J. Lucassen, Tim C. olde Hartman, Willem J.J. Assendelft, and Henny M.J. van Schrojenstein Lantman-de Valk. "Constructing a Health Assessment Questionnaire for People with Intellectual Disabilities: A Cognitive Interview Study." *Journal of Applied Research in Intellectual Disabilities,* 2019, online ahead of print.

Banas, Jennifer R., Susan Magasi, Kim The, and David E. Victorson. "Recruiting and Retaining People with Disabilities for Qualitative Health Research: Challenges and Solutions." *Qualitative Health Research,* vol. 29, no. 7, 2019, pp. 1056–1064.

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.

Beail, Nigel, and Katie Williams. “Using Qualitative Methods in Research with People Who Have Intellectual Disabilities.” *Journal of Applied Research in Intellectual Disabilities,* vol. 27, no. 2, 2014, pp. 85–96.

Bovin, Michelle J., Shimrit K. Black, Paola Rodriguez, Carole A. Lunney, Sarah E. Kleiman, Frank W. Weathers, Paula P. Schnurr, James Spira, Terence M. Keane, and Brian P. Marx. “Development and Validation of a Measure of PTSD-Related Psychosocial Functional Impairment: The Inventory of Psychosocial Functioning.” *Psychological Services,* vol. 15, no. 2, 2018, pp. 216–229.

Caldwell, Kate. “Dyadic Interviewing: A Technique Valuing Interdependence in Interviews with Individuals with Intellectual Disabilities.” *Qualitative Research,* vol. 14, no. 4, 2014, pp. 488–507.

Clarke, Jason, Katherine Prescott, and Rebecca Milne. “How Effective Is the Cognitive Interview When Used with Adults with Intellectual Disabilities Specifically with Conversation Recall?” *Journal of Applied Research in Intellectual Disabilities,* vol. 26, no. 6, 2013, pp. 546–556.

Cridland, Elizabeth K., Lyn Phillipson, Christopher Brennan-Horley, and Kate Swaffer. “Reflections and Recommendations for Conducting In-Depth Interviews with People with Dementia.” *Qualitative Health Research,* vol. 26, no. 13, 2016, pp. 1774–1786.

Curtin, Carol, Linda G. Bandini, Aviva Must, Sarah Phillips, Melissa C.T. Maslin, Charmaine Lo, James M. Gleason, Richard K. Fleming, and Heidi I. Stanish. “Including Youth with Intellectual Disabilities in Health Promotion Research: Development and Reliability of a Structured Interview to Assess the Correlates of Physical Activity Among Youth.” *Journal of Applied Research in Intellectual Disabilities,* vol. 29, no. 4, 2016, pp. 378–386.

Dee-Price, Betty-Jean M., Lorna Hallahan, Diane Nelson Bryen, and Joanne M. Watson. “Every Voice Counts: Exploring Communication Accessible Research Methods.” *Disability & Society,* February 18, 2020.

Digby, Robin, Susan Lee, and Allison Williams. “Interviewing People with Dementia in Hospital: Recommendations for Researchers.” *Journal of Clinical Nursing,* vol. 25, no. 7-8, 2016, pp. 1156–1165.

Eide, Arne H., Karin Dyrstad, Alister Munthali, Gert Van Rooy, Stine H. Braathen, Thomas Halvorsen, Frans Persendt, Peter Mvula, and Jan K. Rød. “Combining Survey Data, GIS and Qualitative Interviews in the Analysis of Health Service Access for Persons with Disabilities.” *BMC International Health and Human Rights,* vol. 18, no. 26, 2018, 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.

Fernandes-Taylor, Sara, Cara Damico Smith, Natalia Arroyo, Kemberlee Bonnet, David Schlundt, Margarete Wichmann, Irene Feurer, and David O. Francis. "Study Protocol to Develop a Patient-Reported Outcome Measuring Disability Associated with Unilateral Vocal Fold Paralysis: A Mixed-Methods Approach with the CoPE Collaborative." *BMJ Open,* vol. 9, 2019, online only.

Frielink, Noud, and Petri Embregts. "Modification of Motivational Interviewing for Use with People with Mild Intellectual Disability and Challenging Behaviour." *Journal of Intellectual & Developmental Disability,* vol. 38, no. 4, 2013, pp. 279–291.

Geister, Thorin L., Manjari Quintanar-Solares, Mona Martin, Stephan Aufhammer, and Friedrich Asmus. "Qualitative Development of the 'Questionnaire on Pain Caused by Spasticity (QPS),' a Pediatric Patient-Reported Outcome for Spasticity-Related Pain in Cerebral Palsy." *Quality of Life Research,* vol. 23, no. 3, 2014, pp. 887–896.

Gibson, Barbara E., Gillian King, Azadeh Kushki, Bhavnita Mistry, Laura Thompson, Gail Teachman, Beata Batorowicz, and Margot McMain-Klein. "A Multi-Method Approach to Studying Activity Setting Participation: Integrating Standardized Questionnaires, Qualitative Methods and Physiological Measures." *Disability and Rehabilitation,* vol. 36, no. 19, 2014, pp. 1652–1660.

Gordon, Mark F., William R. Lenderking, Amy Duhig, Julie Chandler, J. Jason Lundy, David S. Miller, Elisabeth Piault-Louis, Rachelle S. Doody, Douglas Galasko, Serge Gauthier, and Lori Frank. "Development of a Patient-Reported Outcome Instrument to Assess Complex Activities of Daily Living and Interpersonal Functioning in Persons with Mild Cognitive Impairment: The Qualitative Research Phase." *Alzheimer's & Dementia,* vol. 12, no. 1, 2016, pp. 75–84.

Hamilton, Sharynne, Tracy Reibel, Sarah Maslen, Rochelle Watkins, Freeman Jacinta, Hayley Passmore, Raewyn Mutch, Melissa O'Donnell, Valerie Braithwaite, and Carol Bower. "Disability 'In-Justice': The Benefits and Challenges of 'Yarning' with Young People Undergoing Diagnostic Assessment for Fetal Alcohol Spectrum Disorder in a Youth Detention Center." *Qualitative Health Research,* vol. 30, no. 2, 2020, pp. 314–327.

Heffron, Jenna L., Natasha A. Spassiani, Amber M. Angell, and Joy Hammel. "Using Photovoice as a Participatory Method to Identify and Strategize Community Participation with People with Intellectual and Developmental Disabilities." *Scandinavian Journal of Occupational Therapy,* vol. 25, no. 5, 2018, pp. 382-395.

Hollomotz, Andrea. "Successful Interviews with People with Intellectual Disability." *Qualitative Research,* vol. 18, no. 2, 2018, pp. 153–170.

Kaley, Alexandra, Chris Hatton, and Christine Milligan. "More than Words: The Use of Video in Ethnographic Research with People with Intellectual Disabilities." *Qualitative Health Research,* vol. 29, no. 7, 2019, pp. 931–943.

Kalpakjian, Claire Z., Jodi M. Kreschmer, Mary D. Slavin, Pamela A. Kisala, Elisabeth H. Quint, Nancy D. Chiaravalloti, Natalie Jenkins, Tamara Bushnik, Dagmar Amtmann, David S. Tulsky, et al. "Reproductive Health in Women with Physical Disability: A Conceptual Framework for the Development of New Patient-Reported Outcome Measures." *Journal of Women's Health,* vol. 29, no. 11, 2020, pp. 1427–1436.

Kanagasabai, Parimala S., Brigit Mirfin-Veitch, Leigh A. Hale, and Hilda Mulligan. "A Child-Centered Method of Interviewing Children with Movement Impairments." *Physical & Occupational Therapy in Pediatrics,* vol. 38, no. 3, 2018, pp. 255–268.

Kramer, Jessica M., and Ariel E. Schwartz. "Development of the Pediatric Disability Inventory-Patient Reported Outcome (PEDI-PRO) Measurement Conceptual Framework and Item Candidates." *Scandinavian Journal of Occupational Therapy,* vol. 25, no. 5, 2018, pp. 335–346.

Krol, M., H. Sixma, J. Meerdink, H. Wiersma, and J. Rademakers. "Exploring Young Patients' Perspectives on Rehabilitation Care: Methods and Challenges of Organizing Focus Groups for Children and Adolescents." *Child: Care, Health and Development,* vol. 40, no. 4, 2014, pp. 507–514.

Krueger, Alice B., Patrice Colletti, Hillary R. Bogner, Frances K. Barg, and Margaret G. Stineman. "Conducting Focus Groups in Second Life® on Health-Related Topics." *Journal of Alternative Medicine Research,* vol. 9, no. 2, 2017, pp. 135–139.

Liljenquist, Kendra, Jessica Kramer, Zachary Rossetti, and Wendy Coster. "Content Development, Accessibility and Feasibility of a Self-Report Tool for Use in Programmes Serving Youth with Cognitive Disabilities: The Participatory Experience Survey." *Australian Occupational Therapy Journal,* vol. 66, no. 4, 2019, pp. 490–499.

Milne, Rebecca, Stefanie J. Sharman, Martine B. Powell, and Sarah Mead. "Assessing the Effectiveness of the Cognitive Interview for Children with Severe Intellectual Disabilities." *International Journal of Disability, Development and Education,* vol. 60, no. 1, 2013, pp. 18–29.

Mitchell, Fraser. "Reflections on the Process of Conducting Secondary Analysis of Qualitative Data Concerning Informed Choice for Young People with a Disability in Transition." *Forum: Qualitative Social Research,* vol. 16, no. 3, 2015, pp. 1–12.

Nind, Melanie, and Hilra Vinha. "Creative Interactions with Data: Using Visual and Metaphorical Devices in Repeated Focus Groups." *Qualitative Research,* vol. 16, no. 1, 2016, pp. 9–26.

O'Brien, Dai. "Visual Research with Young d/Deaf People - An Investigation of the Transitional Experiences of d/Deaf Young People from Mainstream Schools Using Auto-Driven Photo-Elicitation Interviews." *Graduate Journal of Social Science,* vol. 10, no. 2, 2013, pp. 152–175.

O'Brien, Kelly K., Tarik Bereket, Marilyn Swinton, and Patricia Solomon. "Using Qualitative Methods to Assess the Measurement Property of a New HIV Disability Questionnaire." *International Journal of Qualitative Methods,* vol. 12, no. 1, 2013, 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.

Ottmann, Goetz, and Jenny Crosbie. "Mixed Method Approaches in Open-Ended, Qualitative, Exploratory Research Involving People with Intellectual Disabilities: A Comparative Methods Study." *Journal of Intellectual Disabilities,* vol. 17, no. 3, 2013, pp. 182–197.

Pedersen, H., S. Söderström, and P.S. Kermit. "Assistive Activity Technology as Symbolic Expressions of the Self." *Technology and Disability,* vol. 31, no. 3, 2019, pp. 129–140.

Prior, Sarah, Andrea Miller, Steven Campbell, Karen Linegar, and Gregory Peterson. "The Challenges of Including Patients with Aphasia in Qualitative Research for Health Service Redesign: Qualitative Interview Study." *Journal of Participatory Medicine,* vol. 12, no. 1, 2020, article no. e12336.

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.

Sigstad, Hanne M.H. "Characteristic Interviews, Different Strategies: Methodological Challenges in Qualitative Interviewing Among Respondents with Mild Intellectual Disabilities." *Journal of Intellectual Disabilities,* vol. 18, no. 2, 2014, pp. 188–202.

Sigstad, Hanne M.H., and Veerle Garrels. "Facilitating Qualitative Research Interviews for Respondents with Intellectual Disability." *European Journal of Special Needs Education,* vol. 33, no. 5, 2018, pp. 692–706.

Skyrme, Sarah L., and Simon Woods. "Researching Disabled Children and Young People's Views on Decision-Making: Working Reflexively to Rethink Vulnerability." *Childhood,* vol. 25, no. 3, 2018, pp. 355–368.

Stokes, Jonathan, Christopher J. Evans, Farrah Pompilus, Alan L. Shields, and Kent H. Summers. "Development of a Questionnaire to Assess the Impact of Chronic Low Back Pain for Use in Regulated Clinical Trials." *The Patient,* vol. 6, no. 4, 2013, pp. 291–305.

Swatt, Adam J., Ariel E. Schwartz, and Jessica M. Kramer. "Youth's Perspective of Responsibility: Exploration of a Construct for Measurement with Youth with Developmental Disabilities." *Physical & Occupational Therapy in Pediatrics,* vol. 39, no. 2, 2019, pp. 204–216.

Synnot, Anneliese, Sophie Hill, Michael Summers, and Michael Taylor. "Comparing Face-to-Face and Online Qualitative Research with People with Multiple Sclerosis." *Qualitative Health Research,* vol. 24, no. 3, 2014, pp. 431–438.

Tarzia, Laura, Michael Bauer, Deirdre Fetherstonhaugh, and Rhonda Nay. "Interviewing Older People in Residential Aged Care About Sexuality: Difficulties and Challenges." *Sexuality and Disability,* vol. 31, no. 4, 2013, pp. 361–371.

Teachman, Gail, and Barbara E. Gibson. "Children and Youth with Disabilities: Innovative Methods for Single Qualitative Interviews." *Qualitative Health Research,* vol. 23, no. 2, 2013, pp. 264–274.

Thurman, Whitney A., and Tracie C. Harrison. "Reaching the 'Hard-to-Reach': Recruitment of Rural-Dwelling Adults with Disabilities." *Journal of Transcultural Nursing,* vol. 31, no. 2, 2020, pp. 171–177.

Trevisan, Filippo. "Making Focus Groups Accessible and Inclusive for People with Communication Disabilities: A Research Note." *Qualitative Research,* July 22, 2020.

Verseghy, Judy, Lynda Atack, and Janet Maher. "Key Considerations When Interviewing Individuals with Expressive Language Difficulties." *Qualitative Research,* vol. 20, no. 6, 2020, pp. 960–970.

Williams, Toni L. "Exploring Narratives of Physical Activity and Disability Over Time: A Novel Integrated Qualitative Methods Approach." *Psychology of Sport and Exercise,* vol. 37, 2018, pp. 224–234.

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.

AlHeresh, Rawan, Michael P. LaValley, Wendy Coster, and Julie J. Keysor. "Construct Validity and Scoring Methods of the World Health Organization: Health and Work Performance Questionnaire Among Workers with Arthritis and Rheumatological Conditions." *Journal of Occupational and Environmental Medicine,* vol. 59, no. 6, 2017, pp. e112–e118.

Altman, Barbara M. "Another Perspective: Capturing the Working-Age Population with Disabilities in Survey Measures." *Journal of Disability Policy Studies,* vol. 25, no. 3, 2014, pp. 146–153.

Altman, Barbara M., Jennifer Madans, and Julie D. Weeks. "An Evaluation of the American Community Survey Indicators of Disability." *Disability and Health Journal,* vol. 10, no. 4, 2017, pp. 485–491.

Alvarez-Nebreda, M. Loreto, Marilyn Heng, Bernard Rosner, Michael McTague, Houman Javedan, Mitchel B. Harris, and Michael J. Weaver. "Reliability of Proxy-Reported Patient-Reported Outcomes Measurement Information System Physical Function and Pain Interference Responses for Elderly Patients with Musculoskeletal Injury." *The Journal of the American Academy of Orthopaedic Surgeons,* vol. 27, no. 4, 2019, pp. e156–e165.

Athilingam, Ponrathi, Constance Visovsky, Amanda F. Elliott, and Philip J. Rogal. "Cognitive Screening in Persons with Chronic Diseases in Primary Care: Challenges and Recommendations for Practice." *American Journal of Alzheimer's Disease and Other Dementias,* vol. 30, no. 6, 2015, pp. 547–558.

Attell, Brandon K., Christopher Cappelli, Brigitte Manteuffel, and Hongli Li. "Measuring Functional Impairment in Children and Adolescents: Psychometric Properties of the Columbia Impairment Scale (CIS)." *Evaluation and the Health Professions,* vol. 43, no. 1, 2020, pp. 3–15.

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.

Azevedo, Bruna R., Crystian B. Oliveira, Giulia M.D. Araujo, Fernanda G. Silva, Tatiana M. Damato, Rafael Z. Pinto, and Diego G.D. Christofaro. "Is There Equivalence Between the Electronic and Paper Version of the Questionnaires for Assessment of Patients with Chronic Low Back Pain?" *Spine,* 2018, online ahead of print.

Bailly, Florian, Violaine Foltz, Sylvie Rozenberg, Michael Norberg, Joelle Glemarec, Sophie Pouplin, Beatrice Banneville, Christophe Demoulin, Véronique Gaud-Listrat, Bruno Fautrel, and Laure Gossec. "Development and Validation of a Questionnaire Categorizing Behavioral Strategies in Patients with Chronic Low Back Pain." *Joint, Bone, Spine,* vol. 84, no. 6, 2017, pp. 725–731.

Baker, Ashleigh T., Julie E. Byles, Deborah J. Loxton, Deirdre McLaughlin, Anna Graves, and Annette Dobson. "Utility and Acceptability of the Modified Telephone Interview for Cognitive Status in a Longitudinal Study of Australian Women Aged 85 to 90." *Journal of the American Geriatrics Society,* vol. 61, no. 7, 2013, pp. 1217–1220.

Bakker-van Gijssel, Esther J., Peter L.B.J. Lucassen, Tim C. olde Hartman, Willem J.J. Assendelft, and Henny M.J. van Schrojenstein Lantman-de Valk. "Constructing a Health Assessment Questionnaire for People with Intellectual Disabilities: A Cognitive Interview Study." *Journal of Applied Research in Intellectual Disabilities,* 2019, online ahead of print.

Banks, Lena M., Sian White, Adam Biran, Jane Wilbur, Shailes Neupane, Saurav Neupane, Aditi Sharma, and Hannah Kuper. "Are Current Approaches for Measuring Access to Clean Water and Sanitation Inclusive of People with Disabilities: Comparison of Individual- and Household-Level Access Between People With and Without Disabilities in the Tanahun District of Nepal." *PLOS ONE,* vol. 14, no. 10, 2019, pp. 1–16.

Beaurivage, Daniel, Louis-Philippe Boulet, Juliet M. Foster, Peter G. Gibson, and Vanessa M. McDonald. "Validation of the Patient-Completed Asthma Knowledge Questionnaire (PAKQ)." *Journal of Asthma,* vol. 55, no. 2, 2018, pp. 169–179.

Beckmann, Helen, Matthias Augustin, Christoph Heesen, Jana Poettgen, and Christine Blome. "Benefit Evaluation in Multiple Sclerosis Relapse Treatment from the Patients' Perspective – Development and Validation of a New Questionnaire." *Multiple Sclerosis and Related Disorders,* vol. 28, 2019, pp. 256–261.

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.

Bellalou, Lucie, Naomi Downes, and Emilie Cappe. "Development and Preliminary Validation of a Depressive Symptomatology Detection Scale Among Children and Adolescents on the Autism Spectrum." *Autism*. Published ahead of print, September 21, 2020.

Blake, Grant A. "A New Protocol to Assess the Subjective Wellbeing of Adolescents with Intellectual Disability." *Journal of Policy and Practice in Intellectual Disabilities,* vol. 14, no. 4, 2017, pp. 298–308.

Boal, A.L., C.A. Vaughan, C.S. Sims, and J.N.V. Miles. "Measurement Invariance Across Administration Mode: Examining the Posttraumatic Stress Disorder (PTSD) Checklist." *Psychological Assessment,* vol. 29. No. 1, 2017, pp. 76–86.

Bosch-Baliarda, Marta, Olga Soler Vilageliu, and Pilar Orero. "Toward a Sign Language-Friendly Questionnaire Design." *The Journal of Deaf Studies and Deaf Education,* vol. 24, no. 4, 2019, pp. 333–345.

Boström, Petra, Jakob Å. Johnels, Maria Thorson, and Malin Broberg. "Subjective Mental Health, Peer Relations, Family, and School Environment in Adolescents with Intellectual Developmental Disorder: A First Report of a New Questionnaire Administered on Tablet PCs." *Journal of Mental Health Research in Intellectual Disabilities,* vol. 9, no. 4, 2016, pp. 207–231.

Bourke, John A., Allison Nichols-Dunsmuir, Annabel Begg, Hongfang Dong, and Philip J. Schluter. "Measuring Disability: An Agreement Study Between Two Disability Measures." *Disability and Health Journal,* 2020, article no. 100995.

Bovin, Michelle J., Shimrit K. Black, Paola Rodriguez, Carole A. Lunney, Sarah E. Kleiman, Frank W. Weathers, Paula P. Schnurr, James Spira, Terence M. Keane, and Brian P. Marx. "Development and Validation of a Measure of PTSD-Related Psychosocial Functional Impairment: The Inventory of Psychosocial Functioning." *Psychological Services,* vol. 15, no. 2, 2018, pp. 216–229.

Bozzay, Melanie L., Kimberly N. O'Leary, Alessandro S. De Nadai, Kim Gryglewicz, Gabriela Romero, and Marc S. Karver. "Adolescent Depression: Differential Symptom Presentations in Deaf and Hard-of-Hearing Youth Using the Patient Health Questionnaire-9." *Journal of Deaf Studies and Deaf Education,* vol. 22, no. 2, 2017, pp. 195–203.

Brandt, Diane E., Pei-Shu Ho, Leighton Chan, and Elizabeth K. Rasch. "Conceptualizing Disability in US National Surveys: Application of the World Health Organization's (WHO) International Classification of Functioning, Disability, and Health (ICF) Framework." *Quality of Life Research,* vol. 23, no. 10, 2014, pp. 2663–2671.

Brehmer-Rinderer, Barbara, Elisabeth L. Zeilinger, Ana Radaljevic, and Germain Weber. "The Vienna Frailty Questionnaire for Persons with Intellectual Disabilities—Revised." *Research in Developmental Disabilities,* vol. 34, no. 6, 2013, pp. 1958–1965.

Brogårdh, Christina, and Jan Lexell. "Test-Retest Reliability of the Self-Reported Impairments in Persons with Late Effects of Polio (SIPP) Rating Scale." *PM&R: The Journal of Injury, Function, and Rehabilitation,* vol. 8, no. 5, 2016, pp. 399–404.

Bruno, D., A. Slachevsky, N. Fiorentino, D. S. Rueda, G. Bruno, A. R. Tagle, L. Olavarria, P. Flores, P. Lillo, M. Roca, and T. Torralva. "Argentinian/Chilean Validation of the Spanish-Language Version of Addenbrooke's Cognitive Examination III for Diagnosing Dementia." *Neurología (English Edition),* vol. 35, no. 2, 2020, pp. 82–88.

Bunning, Karen, Ruth Alder, Lydia Proudman, and Harriet Wyborn. "Co-Production and Pilot of a Structured Interview Using Talking Mats® to Survey the Television Viewing Habits and Preferences of Adults and Young People with Learning Disabilities." *British Journal of Learning Disabilities,* vol. 45, no. 1, 2017, pp. 1–11.

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.

Cappa, Claudia, Daniel Mont, Mitchell Loeb, Christina Misunas, Jennifer Madans, Tijana Comic, and Filipa de Castro. "The Development and Testing of a Module on Child Functioning for Identifying Children with Disabilities on Surveys. III: Field Testing." *Disability and Health Journal,* vol. 11, no. 4, 2018, pp. 510–518.

Carvalho, Flávia A., Priscila K. Morelhão, Marcia R. Franco, Chris G. Maher, Rob J.E.M. Smeets, Crystian B. Oliveira, Ismael F. Freitas Júnior, and Rafael Z. Pinto. "Reliability and Validity of Two Multidimensional Self-Reported Physical Activity Questionnaires in People with Chronic Low Back Pain." *Musculoskeletal Science and Practice,* vol. 27, 2017, pp. 65–70.

Carvalho, Janessa O., Beth Springate, Rachel A. Bernier, and Jennifer Davis. "Psychometrics of the AAN Caregiver Driving Safety Questionnaire and Contributors to Caregiver Concern About Driving Safety in Older Adults." *International Psychogeriatrics,* vol. 30, no. 3, 2018, pp. 355–364.

Chiarotto, Alessandro, Carla Vanti, Christine Cedraschi, Silvano Ferrari, Fernanda de Lima e Sà Resende, Raymond W. Ostelo, and Paolo Pillastrini. "Responsiveness and Minimal Important Change of the Pain Self-Efficacy Questionnaire and Short Forms in Patients with Chronic Low Back Pain." *The Journal of Pain,* vol. 17, no. 6, 2016, pp. 707–718.

Chiarotto, Alessandro, Leo D. Roorda, Martine H. Crins, Maarten Boers, Raymond W. Ostelo, and Caroline B. Terwee. "PROMIS Physical Function Short Forms Display Item- and Scale-Level Characteristics at Least as Good as the Roland Morris Disability Questionnaire in Patients with Chronic Low Back Pain." *Archives of Physical Medicine and Rehabilitation,* 2019, online ahead of print.

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.

Cunha-Miranda, Luís, Helena Santos, Cláudia Miguel, Cândida Silva, Filipe Barcelos, Joana Borges, Ricardo Trinca, Vera Vicente, and Tiago Silva. "Validation of Portuguese-Translated Computer Touch-Screen Questionnaires in Patients with Rheumatoid Arthritis and Spondyloarthritis, Compared with Paper Formats." *Rheumatology International,* vol. 35, no. 12, 2015, pp. 2029–2035.

Dahlhamer, James, Julie D. Weeks, Aaron Maitland, and Jennifer H. Madans. "Conceptualizing Disability: An Evaluation of Differences Between the American Community Survey and Washington Group Short Set Questions." Paper presented at the Eleventh Conference on Health Survey Research Methods, Williamsburg, VA, March 2020.

Dahlhamer, James, Julie Weeks, and Jennifer Madans. "Examining Agreement Between Responses to Independent Sets of Disability Measures: A Comparison of the American Community Survey and Washington Group Short Set Questions." Presented at the American Statistical Association Joint Statistical Meetings, Baltimore, MD, August 2017.

Daniel, Matthew R., Susan A. Sadek, and Peter E. Langdon. "The Reliabilty and Validity of a Revised Version of the How I Think Questionnaire for Men Who Have Intellectual Disabilities." *Psychology, Crime & Law,* vol. 24, no. 4, 2018, pp. 379–390.

De Cesarei, Andrea, and Bruno Baldaro. "Doing Online Research Involving University Students with Disabilities: Methodological Issues." *Computers in Human Behavior,* vol. 53, 2015, pp. 374–380.

de Guise, Elaine, Sara Bélanger, Simon Tinawi, Kirsten Anderson, Joanne LeBlanc, Julie Lamoureux, Hé Audrit, and Mitra Feyz. "Usefulness of the Rivermead Postconcussion Symptoms Questionnaire and the Trail-Making Test for Outcome Prediction in Patients with Mild Traumatic Brain Injury." *Applied Neuropsychology: Adult,* vol. 23, no. 3, 2016, pp. 213–222.

Dekkers, Laura M.S., Anika Bexkens, Abe D. Hofman, Paul D. Boeck, Annematt L. Collot d'Escury, and Hilde M. Huizenga. "Formal Modeling of the Resistance to Peer Influence Questionnaire: A Comparison of Adolescent Boys and Girls With and Without Mild-to-Borderline Intellectual Disability." *Assessment,* vol. 26, no. 6, 2019, pp. 1070–1083.

Devandas, Catalina. "The Development and Testing of a Module on Child Functioning for Identifying Children with Disabilities in Surveys." *Disability and Health Journal,* vol. 11, no. 4, 2018, pp. 493–494.

Di Bari, Mauro, Francesco Profili, Stefania Bandinelli, Anna Salvioni, Enrico Mossello, Carla Corridori, Matilde Razzanelli, Teresa Di Fiandra, and Paolo Francesconi. "Screening for Frailty in Older Adults Using a Postal Questionnaire: Rationale, Methods, and Instruments Validation of the INTER-FRAIL Study." *Journal of the American Geriatrics Society,* vol. 62, no. 10, 2014, pp. 1933–1937.

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.

Eccles, Alicia, Reg Morris, and Ian Kneebone. "Psychometric Properties of the Behavioural Outcomes of Anxiety Questionnaire in Stroke Patients with Aphasia." *Clinical Rehabilitation,* vol. 31, no. 3, 2017, pp. 369–378.

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.

Facal, David, Miguel A.R. Carabias, Arturo X. Pereiro, Cristina Lojo-Seoane, María Campos-Magdaleno, Roos J. Jutten, Sietske A.M. Sikkes, and Onésimo Juncos-Rabadán. "Assessing Everyday Activities Across the Dementia Spectrum with the Amsterdam IADL Questionnaire." *Current Alzheimer Research,* vol. 15, no. 13, 2018, pp. 1261–1266.

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.

Farin, Erik, Antje Ullrich, and Michaela Nagl. "Health Education Literacy in Patients with Chronic Musculoskeletal Diseases: Development of a New Questionnaire and Sociodemographic Predictors." *Health Education Research,* vol. 28, no. 6, 2013, pp. 1080–1091.

Farin, Erik, Michaela Nagl, and Antje Ullrich. "The Comprehensibility of Health Education Programs: Questionnaire Development and Results in Patients with Chronic Musculoskeletal Diseases." *Patient Education and Counseling,* vol. 90, no. 2, 2013, pp. 239–246.

Farina, Nicolas, Laura J. Hughes, Amber Watts, and Ruth G. Lowry. "Use of Physical Activity Questionnaires in People with Dementia: A Scoping Review." *Journal of Aging and Physical Activity,* 2018, pp. 1–24.

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.

Fernandes-Taylor, Sara, Cara Damico Smith, Natalia Arroyo, Kemberlee Bonnet, David Schlundt, Margarete Wichmann, Irene Feurer, and David O. Francis. "Study Protocol to Develop a Patient-Reported Outcome Measuring Disability Associated with Unilateral Vocal Fold Paralysis: A Mixed-Methods Approach with the CoPE Collaborative." *BMJ Open,* vol. 9, 2019, online only.

Frentzel, Elizabeth, Ushma Patel, and Graciela Castillo. "How Can We Develop a Survey that Everyone Can Answer? Developing and Cognitively Testing a Survey for Individuals with Physical and Mental Challenges." Presented at the American Association for Public Opinion Research conference, Austin, TX, May 2016.

Galindo-Garre, Francisca, María D. Hidalgo, Georgina Guilera, Oscar Pino, J. Emilio Rojo, and Juana Gómez-Benito. "Modeling the World Health Organization Disability Assessment Schedule II Using Non-Parametric Item Response Models." *International Journal of Methods in Psychiatric Research,* vol. 24, no. 1, 2015, pp. 1–10.

Gan, Shu-Mei, Li-Chen Tung, Chun-Yu Yeh, and Chun-Hou Wang. "ICF-CY Based Assessment Tool for Children with Autism." *Disability and Rehabilitation,* vol. 35, no. 8, 2013, pp. 678–685.

Geister, Thorin L., Manjari Quintanar-Solares, Mona Martin, Stephan Aufhammer, and Friedrich Asmus. "Qualitative Development of the 'Questionnaire on Pain Caused by Spasticity (QPS),' a Pediatric Patient-Reported Outcome for Spasticity-Related Pain in Cerebral Palsy." *Quality of Life Research,* vol. 23, no. 3, 2014, pp. 887–896.

Georgiadou, Ioanna, Anastasia Vlachou, and Panayiota Stavroussi. "Development of the 'Special-Vocational-Education-Service-Quality Scale': Listening to the Voices of Students with Intellectual Disability." *Quality Assurance in Education: An International Perspective,* vol. 28, no. 2, 2020, pp. 89–103.

Giambelluca, Eliana, Monica Panigazzi, Abdo Saade, and Marcello Imbriani. "Assessment of Functional Status and Rehabilitative Strategies in Occupational Therapy: Role of the Groningen Activity Restriction Questionnaire." *Giornale Italiano di Medicina del Lavoro ed Ergonomia,* vol. 41, no. 1, 2019, pp. 52–57.

Gibson, Barbara E., Gillian King, Azadeh Kushki, Bhavnita Mistry, Laura Thompson, Gail Teachman, Beata Batorowicz, and Margot McMain-Klein. "A Multi-Method Approach to Studying Activity Setting Participation: Integrating Standardized Questionnaires, Qualitative Methods and Physiological Measures." *Disability and Rehabilitation,* vol. 36, no. 19, 2014, pp. 1652–1660.

Goegan, Lauren D., Amanda I. Radil, and Lia M. Daniels. "Accessibility in Questionnaire Research: Integrating Universal Design to Increase the Participation of Individuals with Learning Disabilities." *Learning Disabilities,* vol. 16, no. 2, 2019, pp. 177–190.

Gordon, Mark F., William R. Lenderking, Amy Duhig, Julie Chandler, J. Jason Lundy, David S. Miller, Elisabeth Piault-Louis, Rachelle S. Doody, Douglas Galasko, Serge Gauthier, and Lori Frank. "Development of a Patient-Reported Outcome Instrument to Assess Complex Activities of Daily Living and Interpersonal Functioning in Persons with Mild Cognitive Impairment: The Qualitative Research Phase." *Alzheimer's & Dementia,* vol. 12, no. 1, 2016, pp. 75–84.

Goujon, Nicolas, Alexandra Devine, Sally M. Baker, Beth Sprunt, Tanya J. Edmonds, Jennifer K. Booth, and Jill E. Keeffe. "A Comparative Review of Measurement Instruments to Inform and Evaluate Effectiveness of Disability Inclusive Development." *Disability and Rehabilitation,* vol. 36, no. 10, 2014, pp. 804–812.

Hammond, Alison, Yeliz Prior, Mike C. Horton, Alan Tennant, and Sarah Tyson. "The Psychometric Properties of the Evaluation of Daily Activity Questionnaire in Seven Musculoskeletal Conditions." *Disability and Rehabilitation,* vol. 40, no. 17, 2018, pp. 2070–2080.

Havercamp, Susan M., Gloria L. Krahn, Sheryl A. Larson, Glenn Fujiura, Tawara D. Goode, and Barbara L. Kornblau. "Identifying People with Intellectual and Developmental Disabilities in National Population Surveys." *Intellectual and Developmental Disabilities,* vol. 57, no. 5, 2019, pp. 376–389.

Heffernan, Eithne, David W. Maidment, Johanna G. Barry, and Melanie A. Ferguson. "Refinement and Validation of the Social Participation Restrictions Questionnaire: An Application of Rasch Analysis and Traditional Psychometric Analysis Techniques." *Ear and Hearing,* vol. 40, no. 2, 2019, pp. 328–339.

Heffernan, Eithne, Neil S. Coulson, and Melanie A. Ferguson. "Development of the Social Participation Restrictions Questionnaire (SPaRQ) Through Consultation with Adults with Hearing Loss, Researchers, and Clinicians: A Content Evaluation Study." *International Journal of Audiology,* vol. 57, no. 10, 2018, pp. 791–799.

Ho, Lily Y. W., Kenny C. W. Chin, Connie Y. Y. Fung, and Claudia K. Y. Lai. "Validation of the Chinese Non-Pharmacological Therapy Experience Scale in Persons with Intellectual Disability." *Nursing Open,* vol. 7, no. 1, 2020, pp. 390–397.

Honkavaara, Niklas, Amer N. Al-Ani, Pierre Campenfeldt, Wilhelmina Ekström, and Margareta Hedström. "Good Responsiveness with EuroQol 5-Dimension Questionnaire and Short Form (36) Health Survey in 20–69 Years Old Patients with a Femoral Neck Fracture: A 2-Year Prospective Follow-Up Study in 182 Patients." *Injury,* vol. 47, no. 8, 2016, pp. 1692–1697.

Houtenville, Andrew, and Eric Lauer. "Comparing Prevalence Estimates for People with Disabilities in National Surveys: 2009—2014." Presented at the American Statistical Association Joint Statistical Meetings, Chicago, IL, August 2016.

Hughes, Rosemary B., Susan Robinson-Whelen, Rebecca Goe, Michelle Schwartz, Lisa Cesal, Kimberly B. Garner, Katie Arnold, Tina Hunt, and Katherine E. McDonald. "'I Really Want People to Use Our Work to Be Safe'…Using Participatory Research to Develop a Safety Intervention for Adults with Intellectual Disability." *Journal of Intellectual Disabilities,* vol. 24, no. 3, 2020, pp. 309–325.

Iezzoni, Lisa I., Holly Matulewicz, Sarah A. Marsella, Kimberley S. Warsett, Dennis Heaphy, and Karen Donelan. "Collaborative Design of a Health Care Experience Survey for Persons with Disability." *Disability and Health Journal*, vol. 10, no. 2, 2017, pp. 231–239.

Iturregui-Gallardo, Gonzalo, and Jorge L. Méndez-Ulrich. "Towards the Creation of a Tactile Version of the Self-Assessment Manikin (T-SAM) for the Emotional Assessment of Visually Impaired People." *International Journal of Disability, Development and Education,* vol. 67, no. 6, 2020, pp. 657–674.

Iwanaga, Kanako, John Blake, Rana Yaghmaian, Emre Umucu, Fong Chan, Jessica M. Brooks, Maryam Rahimi, and Timothy N. Tansey. "Preliminary Validation of a Short-Form Version of the Attachment Style Questionnaire for Use in Clinical Rehabilitation Counseling Research and Practice." *Rehabilitation Counseling Bulletin,* vol. 61, no. 4, 2018, pp. 205–216.

Jayes, Mark J., and Rebecca L. Palmer. "Stroke Research Staff's Experiences of Seeking Consent from People with Communication Difficulties: Results of a National Online Survey." *Topics in Stroke Rehabilitation,* vol. 21, no. 5, 2014, pp. 443–451.

Jeter, Pamela E., Collin Rozanski, Robert Massof, Olukemi Adeyemo, and Gislin Dagnelie. "Development of the Ultra-Low Vision Visual Functioning Questionnaire (ULV-VFQ)." *Translational Vision Science & Technology,* vol. 6, no. 3, 2017, online.

Katzan, Irene L., Nicolas R. Thompson, Steven Z. George, Sandi Passek, Frederick Frost, and Mary Stilphen. "The Use of STarT Back Screening Tool to Predict Functional Disability Outcomes in Patients Receiving Physical Therapy for Low Back Pain." *The Spine Journal,* vol. 19, no. 4, 2019, pp. 645–654.

Kawata, Ariane K., Asha Hareendran, Shannon Shaffer, Sally Mannix, Andrew Thach, Pooja Desai, Daniel D. Mikol, Brian Ortmeier, Martha Bayliss, and Dawn C. Buse. "Evaluating the Psychometric Properties of the Migraine Functional Impact Questionnaire (MFIQ)." *Headache: The Journal of Head & Face Pain,* vol. 59, no. 8, 2019, pp. 1253–1269.

Khan, Yasmeen, Dana Lawrence, Robert Vining, and Dustin Derby. "Measuring Biopsychosocial Risk for Back Pain Disability in Chiropractic Patients Using the STarT Back Screening Tool: A Cross-Sectional Survey." *Chiropractic & Manual Therapies,* vol. 27, no. 2, 2019, online only.

Koolhaas, Chantal M., Frank J. van Rooij, Magda Cepeda, Henning Tiemeier, Oscar H. Franco, and Josje D. Schoufour. "Physical Activity Derived from Questionnaires and Wrist-Worn Accelerometers: Comparability and the Role of Demographic, Lifestyle, and Health Factors Among a Population-Based Sample of Older Adults." *Clinical Epidemiology,* vol. 10, 2017, pp. 1–16.

Kotwal, Ashwin A., Philip Schumm, David W. Kern, Martha K. McClintock, Linda J. Waite, Joseph W. Shega, Megan J. Huisingh-Scheetz, and William Dale. "Evaluation of a Brief Survey Instrument for Assessing Subtle Differences in Cognitive Function Among Older Adults." *Alzheimer Disease and Associated Disorders,* vol. 29, no. 4, 2015, pp. 317–324.

Kramer, Jessica M., and Ariel E. Schwartz. "Development of the Pediatric Disability Inventory-Patient Reported Outcome (PEDI-PRO) Measurement Conceptual Framework and Item Candidates." *Scandinavian Journal of Occupational Therapy,* vol. 25, no. 5, 2018, pp. 335–346.

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.

Labreche, Tammy, Krithika Nandakumar, Mohammed Althomali, and Susan J. Leat. "Development and Validation of Visual Impairment as a Risk for Falls Questionnaire." *Age and Ageing,* vol. 47, no. 3, 2018, pp. 444–450.

Lauer, Eric A., and Andrew J. Houtenville. "Estimates of Prevalence, Demographic Characteristics and Social Factors Among People with Disabilities in the USA: A Cross-Survey Comparison." *BMJ Open,* vol. 8, 2018, online only.

Lauer, Eric A., Megan Henly, and Rachel Coleman. "Comparing Estimates of Disability Prevalence Using Federal and International Disability Measures in National Surveillance." *Disability and Health Journal,* vol. 12, no. 2, 2019, pp. 195–202.

Leahy, Edmund, Megan Davidson, Deenika Benjamin, and Henry Wajswelner. "Patient-Reported Outcome (PRO) Questionnaires for People with Pain in Any Spine Region. A Systematic Review." *Manual Therapy,* vol. 22, 2016, pp. 22–30.

Lequerica, Anthony H., Nancy D. Chiaravalloti, Angelle M. Sander, Monique R. Pappadis, Juan C. Arango-Lasprilla, Tessa Hart, James H. Baños, Carlos Marquez De La Plata, Flora M. Hammond, and Tanya E. Sherman. "The Community Integration Questionnaire: Factor Structure Across Racial/Ethnic Groups in Persons with Traumatic Brain Injury." *The Journal of Head Trauma Rehabilitation,* vol. 28, no. 6, 2013, pp. E14–E22.

Liljenquist, K., W. Coster, J. Kramer, and Z. Rossetti. "Feasibility of the Participatory Experience Survey and the Setting Affordances Survey for Use in Evaluation of Programmes Serving Youth with Intellectual and Developmental Disabilities." *Child: Care, Health and Development,* vol. 43, no. 4, 2017, pp. 511–517.

Liljenquist, Kendra, Jessica Kramer, Zachary Rossetti, and Wendy Coster. "Content Development, Accessibility and Feasibility of a Self-Report Tool for Use in Programmes Serving Youth with Cognitive Disabilities: The Participatory Experience Survey." *Australian Occupational Therapy Journal,* vol. 66, no. 4, 2019, pp. 490–499.

Lindgren, Noora, Juha O. Rinne, Teemu Palviainen, Jaakko Kaprio, and Eero Vuoksimaa. "Prevalence and Correlates of Dementia and Mild Cognitive Impairment Classified with Different Versions of the Modified Telephone Interview for Cognitive Status (TICS–m)." *International Journal of Geriatric Psychiatry,* vol. 34, no. 12, 2019, pp. 1883–1891.

Liu, Mingnan, Sunghee Lee, Mengyao Hu, and Colleen McClain. "Increasing Cross-National Comparability of Disability Measures with Anchoring Vignettes." Presented at the American Association for Public Opinion Research conference, Anaheim, CA, May 2014.

Livingston, Nicholas A., Tannis Hargrove, Lillie Greiman, Andrew Myers, Catherine Ipsen, and Craig Ravesloot. "An Investigation into the Temporal Scaling of Community Participation Measurement." *Rehabilitation Psychology,* vol. 60, no. 4, 2015, pp. 367–375.

Lloyd, Owen, Tamara Ownsworth, Jennifer Fleming, and Melanie Zimmer-Gembeck. "Development and Preliminary Validation of the Paediatric Awareness Questionnaire for Children and Adolescents with Traumatic Brain Injury." *Child Neuropsychology,* vol. 24, no. 5, 2018, pp. 702–722.

Loeb, Mitchell, Daniel Mont, Claudia Cappa, Elena De Palma, Jennifer Madans, and Roberta Crialesi. "The Development and Testing of a Module on Child Functioning for Identifying Children with Disabilities on Surveys. I: Background." *Disability and Health Journal,* vol. 11, no. 4, 2018, pp. 495–501.

Lutomski, Jennifer E., Maria A.E. Baars, Janneke A. van Kempen, Bianca M. Buurman, Wendy P.J. den Elzen, Aaltje P.D. Jansen, Gertrudis I.J.M. Kempen, Paul F.M. Krabbe, Bas Steunenberg, Ewout W. Steyerberg, Marcel G.M. Olde-Rikkert, and René J.F. Melis. "Validation of a Frailty Index from the Older Persons and Informal Caregivers Survey Minimum Data Set." *Journal of the American Geriatrics Society,* vol. 61, no. 9, 2013, pp. 1625–1627.

Madden, R. H., S. Lukersmith, Q. Zhou, M. Glasgow, and S. Johnston. "Disability-Related Questions for Administrative Datasets." *International Journal of Environmental Research and Public Health,* vol. 17, no. 15, 2020, pp. 1–17.

Manchaiah, Vinaya, Sarah Granberg, Vibhu Grover, Gabrielle H. Saunders, and Deborah Ann Hall. "Content Validity and Readability of Patient-Reported Questionnaire Instruments of Hearing Disability." *International Journal of Audiology,* vol. 59, no. 9, 2019, pp. 565–575.

Margot-Cattin, Isabel, Nicolas Kuhne, Anders Kottorp, Malcolm Cutchin, Annika Öhman, and Louise Nygård. "Development of a Questionnaire to Evaluate Out-of-Home Participation for People with Dementia." *The American Journal of Occupational Therapy,* vol. 73, 2019, online only.

Marino, Molly E., Mark Meterko, Elizabeth E. Marfeo, Christine M. McDonough, Alan M. Jette, Pengsheng Ni, Kara Bogusz, Elizabeth K. Rasch, Diane E. Brandt, and Leighton Chan. "Work-Related Measures of Physical and Behavioral Health Function: Test-Retest Reliability." *Disability and Health Journal,* vol. 8, no. 4, 2015, pp. 652–657.

Marmeleira, José, Luís Laranjo, Olga Marques, and Nuno Batalha. "Criterion-Related Validity of the Short Form of the International Physical Activity Questionnaire in Adults Who Are Blind." *Journal of Visual Impairment & Blindness,* vol. 107, no. 5, 2013, pp. 375–381.

Massey, Meredith. "The Development and Testing of a Module on Child Functioning for Identifying Children with Disabilities on Surveys. II: Question Development and Pretesting." *Disability and Health Journal,* vol. 11, no. 4, 2018, pp. 502–509.

Mathews, Megan, Denis Agniel, Marc N. Elliott, Steven C. Martino, Paul Guerino, Nate Orr, Judy H. Ng, and Megan K. Beckett. "The Development of a Patient-Reported Functional Limitations Index." *American Journal of Managed Care,* vol. 26, no. 7, 2020, pp. e225–e231.

McKenzie, Karen, Dale Metcalfe, and George Murray. "A Review of Measures Used in the Screening, Assessment and Diagnosis of Dementia in People with an Intellectual Disability." *Journal of Applied Research in Intellectual Disabilities,* vol. 31, no. 5, 2018, pp. 725–742.

McKenzie, Karen, George Murray, Aja Murray, Rachel Martin, Yasmin Tanfield, Lauren Delahunty, Linda Hutton, Kara R. Murray, and Anne O'Hare. "Screening for Intellectual Disability with the Child and Adolescent Intellectual Screening Questionnaire: A Modified Delphi Approach." *Developmental Medicine & Child Neurology,* vol. 61, no. 8, 2019, pp. 979–983.

McKenzie, Karen, George Murray, Linda Hutton, Aja Murray, Lauren Delahunty, Anne O'Hare, and Kara Murray. "Child and Adolescent Intellectual Disability Screening Questionnaire to Identify Children with Intellectual Disability." *Developmental Medicine & Child Neurology,* vol. 61, no. 4, 2019, pp. 444–450.

Menezes, Diogo, Luís Laranjo, and José Marmeleira. "Criterion-Related Validity of the Short Form of the International Physical Activity Questionnaire in Adults Who Are Deaf." *Disability and Health Journal,* vol. 10, no. 1, 2017, pp. 33–38.

Mevissen, Liesbeth, Robert Didden, Ad de Jongh, and Hubert Korzilius. "Assessing Posttraumatic Stress Disorder in Adults with Mild Intellectual Disabilities or Borderline Intellectual Functioning." *Journal of Mental Health Research in Intellectual Disabilities,* vol. 13, no. 2, 2020, pp. 110–126.

Morgan, Kerri A., Meghan Gottlieb, Holly H. Hollingsworth, and David B. Gray. "Work Environments of People with Mobility Impairments and Limitations: Mobility Device User Work Survey (MWS)." *Work,* vol. 48, no. 3, 2014, pp. 339–348.

Morin, D., P. Valois, A.G. Crocker, and C. Robitaille. "Development and Psychometric Properties of the Attitudes Toward Intellectual Disability Questionnaire – Short Form." *Journal of Intellectual Disability Research,* vol. 63, no. 6, 2019, pp. 539–547.

Moss, Sarah J., and Stanislaw H. Czyz. "Level of Agreement Between Physical Activity Levels Measured by ActiHeart and the International Physical Activity Questionnaire in Persons with Intellectual Disability." *Disability and Rehabilitation,* vol. 40, no. 3, 2018, pp. 360–366.

Mu, Dong-Liang, Pan-Pan Ding, Shu-Zhe Zhou, Mei-Jing Liu, Xin-Yu Sun, Xue-Ying Li, and Dong-Xin Wang. "Cross-Cultural Adaptation and Validation of the 3D-CAM Chinese Version in Surgical ICU Patients." *BMC Psychiatry,* vol. 20, no. 1, 2020, pp. 1–7.

Nicolaidis, Christina, Dora M. Raymaker, Katherine E. McDonald, Emily M. Lund, Sandra Leotti, Steven K. Kapp, Marsha Katz, Leanne M. Beers, Clarissa Kripke, Joelle Maslak, et al. "Creating Accessible Survey Instruments for Use with Autistic Adults and People with Intellectual Disability: Lessons Learned and Recommendations." *Autism in Adulthood: Challenges and Management,* vol. 2, no. 1, 2020, pp. 61–76.

Nicolaidis, Christina, Dora Raymaker, Marsha Katz, Mary Oschwald, Rebecca Goe, Sandra Leotti, Leah Grantham, Eddie Plourde, Janice Salomon, Rosemary B. Hughes, and Laurie E. Powers. "Community-Based Participatory Research to Adapt Health Measures for Use by People with Developmental Disabilities." *Progress in Community Health Partnerships: Research, Education, and Action,* vol. 9, no. 2, 2015, pp. 157–170.

Nielsen, Anne M., Werner Vach, Peter Kent, Lise Hestbaek, and Alice Kongsted. "Using Existing Questionnaires in Latent Class Analysis: Should We Use Summary Scores or Single Items as Input? A Methodological Study Using a Cohort of Patients with Low Back Pain." *Clinical Epidemiology,* vol. 8, 2016, pp. 73–89.

O'Brien, Kelly K., Ahmed M. Bayoumi, Paul Stratford, and Patricia Solomon. "Which Dimensions of Disability Does the HIV Disability Questionnaire (HDQ) Measure? A Factor Analysis." *Disability and Rehabilitation,* vol. 37, no. 13, 2015, pp. 1193–1201.

O'Brien, Kelly K., Tarik Bereket, Marilyn Swinton, and Patricia Solomon. "Using Qualitative Methods to Assess the Measurement Property of a New HIV Disability Questionnaire." *International Journal of Qualitative Methods,* vol. 12, 2013, online only.

O'Keeffe, Lynsey, Suzanne Guerin, John McEvoy, Karen Lockhart, and Philip Dodd. "The Process of Developing Self-Report Measures in Intellectual Disability: A Case Study of a Complicated Grief Scale." *British Journal of Learning Disabilities,* vol. 47, no. 2, 2019, pp. 134–144.

Paladin, M., T. Kogovšek, and S. Pavlin. "How Do the Particular Characteristics of Less-Educated Employees with Disabilities Impact Survey Implementation?" *Work,* vol. 65, no. 4, 2020, pp. 707–719.

Pérez-Cruzado, D., and A.I. Cuesta-Vargas. "Energy Expenditure Measured with Accelerometers and Self-Report Questionnaire in People with Intellectual Disabilities." *Journal of Intellectual Disability Research,* vol. 62, no. 8, 2018, pp. 701–708.

Perry, Adrienne, Meisha Charles, Busi Ncube, and Jonathan Weiss. "The GO4KIDDS School Satisfaction Scale." *Journal of Applied Research in Intellectual Disabilities,* vol. 32, no. 2, 2019, pp. 471–474.

Phillips, Kimberly, Andrew Houtenville, and Vidya Sundar. "Toward Better Disability Items on National Surveys." Presented at the American Statistical Association Joint Statistical Meetings, Chicago, IL, August 2016.

Pink, Joshua, Stavros Petrou, Esther Williamson, Mark Williams, and Sarah E. Lamb. "Properties of Patient-Reported Outcome Measures in Individuals Following Acute Whiplash Injury." *BMC Health and Quality of Life Outcomes,* vol. 12, no. 38, 2014, online only.

Postma, S.A.E., K. van Boven, H. Ten Napel, D.L. Gerritsen, W.J.J. Assendelft, H. Schers, and T.C. olde Hartman. "The Development of an ICF-Based Questionnaire for Patients with Chronic Conditions in Primary Care." *Journal of Clinical Epidemiology,* vol. 103, 2018, pp. 92–100.

Propp, Roni, Laura McAdam, Aileen M. Davis, Nancy M. Salbach, Shannon Weir, Clarissa Encisa, and Unni G. Narayanan. "Development and Content Validation of the Muscular Dystrophy Child Health Index of Life with Disabilities Questionnaire for Children with Duchenne Muscular Dystrophy." *Developmental Medicine & Child Neurology,* vol. 61, no. 1, 2019, pp. 75–81.

Raggi, Alberto, Venusia Covelli, Erika Guastafierro, Matilde Leonardi, Chiara Scaratti, Licia Grazzi, Marco Bartolini, Giovanna Viticchi, Sabina Cevoli, Giulia Pierangeli, Gioacchino Tedeschi, Antonio Russo, Piero Barbanti, Cinzia Aurilia, Carlo Lovati, Luca Giani, Fabio Frediani, Paola Di Fiore, Francesco Bono, Laura Rapisarda, and Domenico D'Amico. "Validation of a Self-Reported Instrument to Assess Work-Related Difficulties in Patients with Migraine: The HEADWORK Questionnaire." *The Journal of Headache and Pain,* vol. 19, no. 85, 2018, online only.

Rakusa, Martin, Joze Jensterle, and Janez Mlakar. "Clock Drawing Test: A Simple Scoring System for the Accurate Screening of Cognitive Impairment in Patients with Mild Cognitive Impairment and Dementia." *Dementia and Geriatric Cognitive Disorders,* vol. 45, no. 5, 2018, pp. 326–334.

Raley, Sheida K., Karrie A. Shogren, Graham G. Rifenbark, Mark H. Anderson, and Leslie A. Shaw. "Comparing the Impact of Online and Paper-and-Pencil Administration of the Self-Determination Inventory: Student Report." *Journal of Special Education Technology,* vol. 35, no. 3, 2020, pp. 133–144.

Rand, Stacey, James Caiels, Grace Collins, and Julien Forder. "Developing a Proxy Version of the Adult Social Care Outcome Toolkit (ASCOT)." *BMC Health and Quality of Life Outcomes,* vol. 15, no. 108, 2017, online only.

Robinson-Cimpian, Joseph. "Inaccurate Estimation of Disparities Due to Mischievous Responders: Several Suggestions to Assess Conclusions." *Educational Researcher,* vol. 43, no. 4, 2014, pp. 171–185.

Sabariego, Carla, Cornelia Oberhauser, Aleksandra Posarac, Jerome Bickenbach, Nenad Kostanjsek, Somnath Chatterji, Alana Officer, Michaela Coenen, Lay Chhan, and Alarcos Cieza. "Measuring Disability: Comparing the Impact of Two Data Collection Approaches on Disability Rates." *International Journal of Environmental Research and Public Health,* vol. 12, no. 9, 2015, pp. 10329–10351.

Sander, Angelle M., Allison N. Clark, Laura M. van Veldhoven, Robin Hanks, Tessa Hart, Luis L. Novelo, Esther Ngan, and David B. Arciniegas. "Factor Analysis of the Everyday Memory Questionnaire in Persons with Traumatic Brain Injury." *Clinical Neuropsychologist,* vol. 32, no. 3, 2018, pp. 495–509.

Schwartz, Ariel E., and Jessica M. Kramer. "Inclusive Approaches to Developing Content Valid Patient-Reported Outcome Measure Response Scales for Youth with Intellectual/Developmental Disabilities." *British Journal of Learning Disabilities.* Published ahead of print, October 6, 2020.

Sleijser-Koehorst, Marije L.S., Lisette Bijker, Pim Cuijpers, Gwendolyne G.M. Scholten-Peeters, and Michel W. Coppieters. "Preferred Self-Administered Questionnaires to Assess Fear of Movement, Coping, Self-Efficacy, and Catastrophizing in Patients with Musculoskeletal Pain - A Modified Delphi Study." *Pain,* vol. 160, no. 3, 2018, pp. 600–606.

Sola-Valls, Nuria, Helena Arino, Domingo Escudero, Elisabeth Solana, Albert Llado, Raquel Sanchez-Valle, Yolanda Blanco, Albert Saiz, Josep Dalmau, and Francesc Graus. "Telemedicine Assessment of Long-Term Cognitive and Functional Status in Anti-Leucine-Rich, Glioma-Inactivated 1 Encephalitis." *Neurology Neuroimmunology & Neuroinflammation,* vol. 7, no. 2, 2020.

Stack, Rebecca J., Christian D. Mallen, Chris Deighton, Patrick Kiely, Karen L. Shaw, Alison Booth, Kanta Kumar, Susan Thomas, Ian Rowan, Rob Horne, Peter Nightingale, Sandy Herron-Marx, Clare Jinks, and Karim Raza. "The Development and Initial Validation of a Questionnaire to Measure Help-Seeking Behaviour in Patients with New Onset Rheumatoid Arthritis." *Health Expectations,* vol. 18, no. 6, 2015, pp. 2340–2355.

Stancliffe, Roger J., Renáta Tichá, Sheryl A. Larson, Amy S. Hewitt, and Derek Nord. "Responsiveness to Self-Report Interview Questions by Adults with Intellectual and Developmental Disability." *Intellectual and Developmental Disabilities,* vol. 53, no. 3, 2015, pp. 163–181.

Stavrakantonaki, Marina, and Timothy P. Johnson. "Effects of Rosa's Law on Intellectual-Disability Reporting." *Public Opinion Quarterly,* vol. 82, no. 3, 2018, pp. 593–604.

Stokes, Jonathan, Christopher J. Evans, Farrah Pompilus, Alan L. Shields, and Kent H. Summers. "Development of a Questionnaire to Assess the Impact of Chronic Low Back Pain for Use in Regulated Clinical Trials." *The Patient,* vol. 6, no. 4, 2013, pp. 291–305.

Takenoshita, S., S. Terada, R. Kuwano, T. Inoue, T. Kurozumi, A. Choju, S. Suemitsu, and N. Yamada. "Validation of the Japanese Version of the Dementia Screening Questionnaire for Individuals with Intellectual Disabilities." *Journal of Intellectual Disability Research,* vol. 64, no. 12, 2020, pp. 970–979.

van den Broek, Martin D., Linda Monaci, and Jared G. Smith. "Personal Problems Questionnaire (PPQ): Normative Data and Utility in Assessing Acquired Neurological Impairment." *Archives of Clinical Neuropsychology,* vol. 34, no. 5, 2019, pp. 625–636.

Van Houtven, Courtney H., Steven J. Lippmann, Emmanuelle Belanger, Valerie A. Smith, Hailey J. James, Megan Shepherd-Banigan, Eric Jutkowitz, Emily O'Brien, Jennifer L. Wolff, James R. Burke, et al. "Measurement Properties of the CAPACITY Instrument to Assess Perceived Communication with the Health Care Team Among Care Partners of Patients with Cognitive Impairment." *Medical Care,* vol. 58, no. 9, 2020, pp. 842–849.

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.

Viklund, Henrik, Birgitta Ausén, Göran Hagman, and Lisa B. Thorell. "The Executive Checklist (EC-10) – a New Rating Instrument for Clinicians Assessing Dysexecutive Behavior." *Applied Neuropsychology: Adult.* Published ahead of print, September 16, 2019.

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

Wager, J., F. Barth, L. Stahlschmidt, and B. Zernikow. "Testing the Validity of Telephone Interviews to Assess Chronic Pain in Children and Adolescents: A Randomized Cross-Over Trial." *European Journal of Pain,* vol. 21, no. 10, 2017, pp. 1707–1716.

Walker, Lorraine O., Heather Becker, Erin E. Andrews, and Carolyn S. Phillips. "Adapting a Health Behavioral Change and Psychosocial Toolkit to the Context of Physical Disabilities: Lessons Learned from Disabled Women with Young Children." *Disability & Health Journal,* vol. 14, no. 1, 2021, online ahead of print.

Wand, Benedict M., Mark J. Catley, Martin I. Rabey, Peter B. O'Sullivan, Neil E. O'Connell, and Anne J. Smith. "Disrupted Self-Perception in People with Chronic Low Back Pain. Further Evaluation of the Fremantle Back Awareness Questionnaire." *The Journal of Pain,* vol. 17, no. 9, 2016, pp. 1001–1012.

Ward, Bryce, Andrew Myers, Jennifer Wong, and Craig Ravesloot. "Disability Items from the Current Population Survey (2008–2015) and Permanent Versus Temporary Disability Status." *American Journal of Public Health,* vol. 107, no. 5, 2017, pp. 706–708.

Warden, Clara, Katherine Yun, and Wagahta Semere. "Using the Children with Special Health Care Needs Screener with Immigrant Families: An Analysis of the National Survey of Children's Health." *Journal of Immigrant and Minority Health,* vol. 21, no. 1, 2019, pp. 189–197.

Yang, Ming, Xiang Ding, and Birong Dong. "The Measurement of Disability in the Elderly: A Systematic Review of Self-Reported Questionnaires." *Journal of the American Medical Directors Association,* vol. 15, no. 2, 2014, pp. 150.e1–150.e9.\

2. Measuring Satisfaction and Quality of Life

Arons, Alexander, Paul Krabbe, Gert Wilt, Marcel Olde Rikkert, and Eddy Adang. "Visual Analogue Scales: Scale Recalibration by Patients with Dementia and Their Proxies." *Quality of Life Research,* vol. 22, no. 5, 2013, pp. 979–986.

Barrios, Polaris, Ricardo González, Sherrie Hanna, Angela Lunde, Julie Fields, Dona Locke, and Glenn Smith. "Priority of Treatment Outcomes for Caregivers and Patients with Mild Cognitive Impairment: Preliminary Analyses." *Neurology & Therapy,* vol. 5, no. 2, 2016, pp. 183–192.

Bertelli, Marco O., Annamaria Bianco, Andrea Rossi, Michele Mancini, Giampaolo La Malfa, and Ivan Brown. "Impact of Severe Intellectual Disability on Proxy Instrumental Assessment of Quality of Life." *Journal of Intellectual & Developmental Disability,* vol. 44, no. 3, 2019, pp. 272–281.

Blake, Grant A. "A New Protocol to Assess the Subjective Wellbeing of Adolescents with Intellectual Disability." *Journal of Policy and Practice in Intellectual Disabilities,* vol. 14, no. 4, 2017, pp. 298–308.

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.

Clark, Lauren, Marjorie A. Pett, Elizabeth M. Cardell, Jia-Wen Guo, Erin Johnson, and Jia-Wen Guo. "Developing a Health-Related Quality-of-Life Measure for People with Intellectual Disability." *Intellectual & Developmental Disabilities,* vol. 55, no. 3, 2017, pp. 140–153.

Davis, Jennifer C., Ging-Yuek Hsiung, Stirling Bryan, Claudia Jacova, Patrizio Jacova, Michelle Munkacsy, Winnie Cheung, Philip Lee, and Teresa Liu-Ambrose. "Agreement Between Patient and Proxy Assessments of Quality of Life Among Older Adults with Vascular Cognitive Impairment Using the EQ-5D-3L and ICECAP-O." *PLoS ONE,* vol. 11, no. 4, 2016, online only.

de Geus-Neelen, Karin C.J.M., Wietske M.W.J. van Oorsouw, Lex A.H.C. Hendriks, and Petri J.C.M. Embregts. "Perceptions of Staff and Family of the Quality of Life of People with Severe to Profound Intellectual Disability." *Journal of Intellectual & Developmental Disability,* vol. 44, no. 1, 2019, pp. 42–50.

Dean, Katherine, Crispin Jenkinson, Gordon Wilcock, and Zuzana Walker. "The Development and Validation of a Patient-Reported Quality of Life Measure for People with Mild Cognitive Impairment." *International Psychogeriatrics,* vol. 26, no. 3, 2014, pp. 487–497.

Dean, Katherine, Zuzana Walker, and Crispin Jenkinson. "Data Quality, Floor and Ceiling Effects, and Test-Retest Reliability of the Mild Cognitive Impairment Questionnaire." *Patient Related Outcome Measures,* vol. 9, 2018, pp. 43–47.

Deroche, Chelsea B., Margaret M. Holland, Suzanne McDermott, Julie A. Royer, James W. Hardin, Joshua R. Mann, Deborah Salzberg, Orgul Ozturk, and Lijing Ouyang. "Development of a Tool to Describe Overall Health, Social Independence and Activity Limitation of Adolescents and Young Adults with Disability." *Research in Developmental Disabilities,* vol. 38, 2015, pp. 288–300.

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 and Psychiatric Epidemiology.* Published ahead of print, September 14, 2020.

Fenwick, Eva K., Ryan E.K. Man, Gwyn Rees, Jill Keeffe, Tien Wong, Tien Y. Wong, and Ecosse L. Lamoureux. "Reducing Respondent Burden: Validation of the Brief Impact of Vision Impairment Questionnaire." *Quality of Life Research,* vol. 26, no. 2, 2017, pp. 479–488.

Ferretti, Lisa A., and Philip McCallion. "Translating the Chronic Disease Self-Management Program for Community-Dwelling Adults with Developmental Disabilities." *Journal of Aging & Health,* vol. 31, suppl. 10, 2019, pp. 22S–38S.

Ferro, Mark A., Shane W. Goodwin, Mark Sabaz, and Kathy N. Speechley. "Measurement Equivalence of the Newly Developed Quality of Life in Childhood Epilepsy Questionnaire (QOLCE-55)." *Epilepsia,* vol. 57, no. 3, 2016, pp. 427–435.

Finger, Robert P., Betty Tellis, Julie Crewe, Jill E. Keeffe, Lauren N. Ayton, and Robyn H. Guymer. "Developing the Impact of Vision Impairment - Very Low Vision (IVI-VLV) Questionnaire as Part of the LoVADA Protocol." *Investigative Ophthalmology & Visual Science,* vol. 55, no. 10, 2014, pp. 6150–6158.

Formisano, Rita, Eloise Longo, Eva Azicnuda, Daniela Silvestro, Mariagrazia D'Ippolito, Jean-Luc Truelle, Lindsay Wilson, Jessica Rigon, Carmen Barba, Antonio Forcina, Marco Giustini, Nicole von Steinbüchel, and Klaus von Wild. "Quality of Life in Persons After Traumatic Brain Injury as Self-Perceived and as Perceived by the Caregivers." *Neurological Sciences,* vol. 38, no. 2, 2017, pp. 279–286.

Fox, Rina S., John D. Peipert, Montserrat Vera-Llonch, Glenn Phillips, and David Cella. "PROMIS® and Neuro-QoL™ Measures Are Valid Measures of Health-Related Quality of Life Among Patients with Familial Chylomicronemia Syndrome." *Expert Review of Cardiovascular Therapy,* vol. 18, no. 4, 2020, pp. 231–238.

Friedman, Carli. "The Personal Outcome Measures®." *Disability and Health Journal,* vol. 11, no. 3, 2018, pp. 351–358.

Girard, V., A. Tinland, J.P. Bonin, F. Olive, J. Poule, C. Lancon, T. Apostolidis, M. Rowe, T. Greacen, and M.C. Simeoni. "Relevance of a Subjective Quality of Life Questionnaire for Long-Term Homeless Persons with Schizophrenia." *BMC Psychiatry,* vol. 17, no. 72, 2017, online only.

Gleeson, Michael, Catherine Sherrington, Serigne Lo, Robin Auld, and Lisa Keay. "Impact of the Alexander Technique on Well-Being: A Randomised Controlled Trial Involving Older Adults with Visual Impairment." *Clinical and Experimental Optometry,* vol. 100, no. 6, 2017, pp. 633–641.

Gómez, Laura E., M. L. Morán, M. Á. Alcedo, Víctor B. Arias, and Miguel-Ángel Verdugo. "Addressing Quality of Life of Children with Autism Spectrum Disorder and Intellectual Disability." *Intellectual & Developmental Disabilities,* vol. 58, no. 5, 2020, pp. 393–408.

Gomez-Gallego, M., J. Gomez-Garcia, and E. Ato-Lozano. "Addressing the Bias Problem in the Assessment of the Quality of Life of Patients with Dementia: Determinants of the Accuracy and Precision of the Proxy Ratings." *The Journal of Nutrition, Health & Aging,* vol. 19, no. 3, 2015, pp. 365–372.

Goujon, Nicolas, Alexandra Devine, Sally M. Baker, Beth Sprunt, Tanya J. Edmonds, Jennifer K. Booth, and Jill E. Keeffe. "A Comparative Review of Measurement Instruments to Inform and Evaluate Effectiveness of Disability Inclusive Development." *Disability and Rehabilitation,* vol. 36, no. 10, 2014, pp. 804–812.

Gregersen, Merete, Mette M. Jordansen, and Debby L. Gerritsen. "Overall Quality of Life (OQoL) Questionnaire in Frail Elderly: A Study of Reproducibility and Responsiveness of the Depression List (DL)." *Archives of Gerontology and Geriatrics,* vol. 60, no. 1, 2015, pp. 22–27.

Guilera, Georgina, Juana Gómez-Benito, Óscar Pino, Emilio Rojo, Eduard Vieta, Manuel J. Cuesta, Scot E. Purdon, Miguel Bernardo, Benedicto Crespo-Facorro, Manuel Franco, Anabel Martínez-Arán, Gemma Safont, Rafael Tabarés-Seisdedos, and Javier Rejas. "Disability in Bipolar I Disorder: The 36-Item World Health Organization Disability Assessment Schedule 2.0." *Journal of Affective Disorders,* vol. 174, 2015, pp. 353–360.

Györi, Eva, Christopher Przestrzelski, Igor Pona, Michael Hagmann, Thomas Rath, Christine Radtke, and C.-H. John Tzou. "Quality of Life and Functional Assessment of Facial Palsy Patients: A Questionnaire Study." *International Journal of Surgery,* vol. 55, 2018, pp. 92–97.

Hendriks, A.A. Jolijn, Sarah C. Smith, Theopisti Chrysanthaki, and Nick Black. "Reliability and Validity of a Self-Administration Version of DEMQOL-Proxy." *International Journal of Geriatric Psychiatry,* vol. 32, no. 7, 2017, pp. 734–741.

Hoffman, Michael F., Ivette Cejas, and Alexandra L. Quittner. "Health-Related Quality of Life Instruments for Children with Cochlear Implants: Development of Child and Parent-Proxy Measures." *Ear and Hearing,* vol. 40, no. 3, 2019, pp. 592–604.

Honkavaara, Niklas, Amer N. Al-Ani, Pierre Campenfeldt, Wilhelmina Ekström, and Margareta Hedström. "Good Responsiveness with EuroQol 5-Dimension Questionnaire and Short Form (36) Health Survey in 20–69 Years Old Patients with a Femoral Neck Fracture: A 2-Year Prospective Follow-Up Study in 182 Patients." *Injury,* vol. 47, no. 8, 2016, pp. 1692–1697.

Hornsby, Benjamin W.Y., Samantha J. Gustafson, Hope Lancaster, Sun-Joo Cho, Stephen Camarata, and Fred H. Bess. "Subjective Fatigue in Children with Hearing Loss Assessed Using Self- and Parent-Proxy Report." *American Journal of Audiology,* vol. 26, 2017, pp. 393–407.

Iorio-Morin, Christian, Vanessa K. Noonan, Barry White, Luc Noreau, Jean Leblond, Frédéric S. Dumont, Brian K. Kwon, Marcel F. Dvorak, and Nicolas Dea. "Quality of Life and Health Utility Scores Among Canadians Living with Traumatic Spinal Cord Injury – A National Cross-Sectional Study." *Spine,* vol. 43, no. 14, 2018, pp. 999–1006.

Jahagirdar, Deepa, Thilo Kroll, Karen Ritchie, and Sally Wyke. "Patient-Reported Outcome Measures for Chronic Obstructive Pulmonary Disease: The Exclusion of People with Low Literacy Skills and Learning Disabilities." *The Patient,* vol. 6, no. 1, 2013, pp. 11–21.

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.

Knüppel, Ane, Gry K. Telléus, Helle Jakobsen, and Marlene B. Lauritsen. "Quality of Life in Adolescents and Adults with Autism Spectrum Disorder: Results from a Nationwide Danish Survey Using Self-Reports and Parental Proxy-Reports." *Research in Developmental Disabilities,* vol. 83, 2018, pp. 247–259.

Kocman, A., and G. Weber. "Concepts of Job Satisfaction in People with Intellectual Disability." *Journal of Intellectual Disability Research,* vol. 62, no. 9, 2018, pp. 814–819.

Kozlowski, Allan J., Ritika Singh, David Victorson, Ana Miskovic, Jin-Shei Lai, Richard L. Harvey, David Cella, and Allen W. Heinemann. "Agreement Between Responses from Community-Dwelling Persons with Stroke and Their Proxies on the NIH Neurological Quality of Life (Neuro-QoL) Short Forms." *Archives of Physical Medicine and Rehabilitation,* vol. 96, no. 11, 2015, pp. 1986–1992.

Krops, Leonie A., Linda Wolthuizen, Pieter U. Dijkstra, Eva A. Jaarsma, Jan H.B. Geertzen, and Rienk Dekker. "Reliability of Translation of the RAND 36-Item Health Survey in a Post-Rehabilitation Population." *International Journal of Rehabilitation Research,* vol. 41, no. 2, 2018, pp. 128–137.

Kyrölä, Kati, Arja H. Häkkinen, Jari Ylinen, and Jussi P. Repo. "Further Validation of the Scoliosis Research Society (SRS-30) Questionnaire Among Adult Patients with Degenerative Spinal Disorder." *Disability and Rehabilitation,* 2019, online ahead of print.

Lima-Castro, Sandra, Vanessa Blanco, Patricia Otero, Lara López, and Fernando L. Vázquez. "Health-Related Quality of Life Among Persons with Physical Disabilities: A Systematic Review and Meta-Analysis." *Revista Iberoamericana De Psicología y Salud,* vol. 11, no. 2, 2020, pp. 82–102.

Mack, Jennifer W., Molly McFatrich, Janice S. Withycombe, Scott H. Maurer, Shana S. Jacobs, Li Lin, Nicole R. Lucas, Justin N. Baker, Courtney M. Mann, Lillian Sung, et al. "Agreement Between Child Self-Report and Caregiver-Proxy Report for Symptoms and Functioning of Children Undergoing Cancer Treatment." *JAMA Pediatrics,* vol. 174, no. 11, 2020, online only.

Markowitz, Leslie A., Charina Reyes, Rebecca A. Embacher, Leslie L. Speer, Nancy Roizen, and Thomas W. Frazier. "Development and Psychometric Evaluation of a Psychosocial Quality-of-Life Questionnaire for Individuals with Autism and Related Developmental Disorders." *Autism,* vol. 20, no. 7, 2016, pp. 832–844.

Mensch, S.M., M.A. Echteld, R. Lemmens, A. Oppewal, H.M. Evenhuis, and E.A.A. Rameckers. "The Relationship Between Motor Abilities and Quality of Life in Children with Severe Multiple Disabilities." *Journal of Intellectual Disability Research,* vol. 63, no. 2, 2019, pp. 100–112.

Michel, Pierre, Karine Baumstarck, Christophe Lancon, Badih Ghattas, Anderson Loundou, Pascal Auquier, and Laurent Boyer. "Modernizing Quality of Life Assessment: Development of a Multidimensional Computerized Adaptive Questionnaire for Patients with Schizophrenia." *Quality of Life Research,* vol. 27, no. 4, 2018, pp. 1041–1054.

Nicholas, Marjorie, Lindsay Jennelle, Lisa T. Connor, Charles Haynes, and Lauryn Zipse. "Do Caregiver Proxy Reports and Congruence of Client-proxy Activity Participation Goals Relate to Quality of Life in People with Aphasia?" *International Journal of Language & Communication Disorders,* vol. 55, no. 3, 2020, pp. 373–386.

Niemensivu, Riina, Risto P. Roine, Harri Sintonen, and Erna Kentala. "Health-Related Quality of Life in Hearing-Impaired Adolescents and Children." *Acta Oto-Laryngologica,* vol. 138, no. 7, 2018, pp. 652–658.

Nilsen, Marci L., Lingyun Lyu, Michael A. Belsky, Leila J. Mady, Dan P. Zandberg, David A. Clump, Heath D. Skinner, Shyamal D. Peddada, Susan George, and Jonas T. Johnson. "Impact of Neck Disability on Health-Related Quality of Life Among Head and Neck Cancer Survivors." *Otolaryngology–Head and Neck Surgery,* vol. 162, no. 1, 2020, pp. 64–72.

Pardo-Guijarro, María J., Bencie Woll, Pablo Moya-Martínez, María Martínez-Andrés, Eugenio E. Cortés-Ramírez, and Vicente Martínez-Vizcaíno. "Validity and Reliability of the Spanish Sign Language Version of the KIDSCREEN-27 Health-Related Quality of Life Questionnaire for Use in Deaf Children and Adolescents." *Gaceta Sanitaria,* vol. 27, no. 4, 2013, pp. 318–324.

Perry, Adrienne, Meisha Charles, Busi Ncube, and Jonathan Weiss. "The GO4KIDDS School Satisfaction Scale." *Journal of Applied Research in Intellectual Disabilities,* vol. 32, no. 2, 2019, pp. 471–474.

Raczka, Roman, Kate Theodore, and Janice Williams. "An Initial Validation of a New Quality of Life Measure for Adults with Intellectual Disability: The Mini-MANS-LD." *Journal of Intellectual Disabilities,* vol. 24, no. 2, 2020, pp. 177–193.

Rand, Stacey, James Caiels, Grace Collins, and Julien Forder. "Developing a Proxy Version of the Adult Social Care Outcome Toolkit (ASCOT)." *BMC Health and Quality of Life Outcomes,* vol. 15, no. 108, 2017, online only.

Raven-Takken, Evelijn, Nicole Ter Wal, and Lizet Van Ewijk. "What Minimum Level of Language Comprehension Is Required for Reliable Administration of the SAQOL-39NLg?" *Aphasiology,* vol. 34, no. 6, 2020, pp. 674–687.

Rietdijk, Rachael, Emma Power, Melissa Brunner, and Leanne Togher. "Reliability of Videoconferencing Administration of a Communication Questionnaire to People with Traumatic Brain Injury and Their Close Others." *The Journal of Head Trauma Rehabilitation,* vol. 32, no. 6, 2017, pp. E38–E44.

Robertson, Jane M. "Using Carer Biographical Narratives to Explore Factors Involved in Proxy Reporting of Quality of Life in People with Dementia." *Aging & Mental Health,* vol. 21, no. 4, 2017, pp. 416–425.

Schwartz, Carolyn, Armon Ayandeh, Jonathan Rodgers, Paul Duberstein, Bianca Weinstock-Guttman, Ralph Benedict, Carolyn E. Schwartz, Jonathan D. Rodgers, and Ralph H.B. Benedict. "A New Perspective on Proxy Report: Investigating Implicit Processes of Understanding Through Patient-Proxy Congruence." *Quality of Life Research,* vol. 24, no. 11, 2015, pp. 2637–2649.

Sexton, Eithne, Mary-Ann O'Donovan, Niamh Mulryan, Philip McCallion, and Mary McCarron. "Whose Quality of Life? A Comparison of Measures of Self-Determination and Emotional Wellbeing in Research with Older Adults with and without Intellectual Disability." *Journal of Intellectual and Developmental Disability,* vol. 41, no. 4, 2016, pp. 324–337.

Silva, Soraia M., Fernanda I. Corrêa, Gabriela S. Pereira, Christina Danielli Coelho de Morais Faria, and João C.F. Corrêa. “Construct Validity of the Items on the Stroke Specific Quality of Life (SS-QOL) Questionnaire that Evaluate the Participation Component of the International Classification of Functioning, Disability and Health.” *Disability and Rehabilitation,* vol. 40, no. 2, 2018, pp. 225–231.

Simões, Cristina, and Sofia Santos. “The Quality of Life Perceptions of People with Intellectual Disability and Their Proxies.” *Journal of Intellectual & Developmental Disability,* vol. 41, no. 4, 2016, pp. 311–323.

Smith, S. C., A. A. J. Hendriks, S. J. Cano, and N. Black. “Proxy Reporting of Health-Related Quality of Life for People with Dementia: A Psychometric Solution.” *Health & Quality of Life Outcomes,* vol. 18, no. 1, 2020, pp. 1–10.

Soares, E. M., T. Granjo, S. Monteiro, S. Bemposta, and A. Salvador. “Accessible Communication in the Transport of Non-Urgent People with Communication Impairments.” *European Journal of Public Health,* vol. 30, suppl. 2, 2020.

Stokes, Jonathan, Christopher J. Evans, Farrah Pompilus, Alan L. Shields, and Kent H. Summers. “Development of a Questionnaire to Assess the Impact of Chronic Low Back Pain for Use in Regulated Clinical Trials.” *The Patient,* vol. 6, no. 4, 2013, pp. 291–305.

Teresi, Jeanne A., Katja Ocepek-Welikson, John A. Toner, Marjorie Kleinman, Mildred Ramirez, Joseph P. Eimicke, Barry J. Gurland, and Albert Siu. “Methodological Issues in Measuring Subjective Well-Being and Quality-of-Life: Applications to Assessment of Affect in Older, Chronically and Cognitively Impaired, Ethnically Diverse Groups Using the Feeling Tone Questionnaire.” *Applied Research in Quality of Life,* vol. 12, no. 2, 2017, pp. 251–288.

Weaver, Meaghann S., Rewais Hanna, Scott Hetzel, Karen Patterson, Alice Yuroff, Sarah Sund, Meredith Schultz, Mary Schroth, and Matthew A. Halanski. “A Prospective, Crossover Survey Study of Child- and Proxy-Reported Quality of Life According to Spinal Muscular Atrophy Type and Medical Interventions.” *Journal of Child Neurology,* vol. 35, no. 5, 2020, pp. 322–330.

Zur, Oz, and Eli Carmeli. “The University of California Los Angeles Dizziness Questionnaire: Advantages and Disadvantages.” *Journal of Vestibular Research,* vol. 23, no. 6, 2013, pp. 279–283.

D. Sampling and Nonresponse

Adams, Dawn, Louise Handley, Mary Heald, Doug Simkiss, Alison Jones, Emily Walls, and Chris Oliver. "A Comparison of Two Methods for Recruiting Children with an Intellectual Disability." *Journal of Applied Research in Intellectual Disabilities,* vol. 30, no. 4, 2017, pp. 696–704.

Blakeslee, Jennifer E., A. Del Quest, Jennifer Powers, Laurie E. Powers, Sarah Geenen, May Nelson, Lawrence D. Dalton, and Elizabeth McHugh. "Reaching Everyone: Promoting the Inclusion of Youth with Disabilities in Evaluating Foster Care Outcomes." *Children and Youth Services Review,* vol. 35, no. 11, 2013, pp. 1801–1808.

De Cesarei, Andrea, and Bruno Baldaro. "Doing Online Research Involving University Students with Disabilities: Methodological Issues." *Computers in Human Behavior,* vol. 53, 2015, pp. 374–380.

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.

Gaertner, Beate, Ina Seitz, Judith Fuchs, Markus A. Busch, Martin Holzhausen, Peter Martus, and Christa Scheidt-Nave. "Baseline Participation in a Health Examination Survey of the Population 65 Years and Older: Who Is Missed and Why?" *BMC Geriatrics,* vol. 16, no. 21, 2016, online only.

Gaskin, Cadeyrn J., Sylvie D. Lambert, Steven J. Bowe, and Liliana Orellana. "Why Sample Selection Matters in Exploratory Factor Analysis: Implications for the 12-Item World Health Organization Disability Assessment Schedule 2.0." *BMC Medical Research Methodology,* vol. 17, no. 40, 2017, online only.

Ghandour, Reem M., Jessica R. Jones, Lydie A. Lebrun-Harris, Jessica Minnaert, Stephen J. Blumberg, Jason Fields, Christina Bethell, and Michael D. Kogan. "The Design and Implementation of the 2016 National Survey of Children's Health." *Maternal and Child Health Journal,* vol. 22, no. 8, 2018, pp. 1093–1102.

Gosling, Amanda, and Eirini-Christina Saloniki. "Correction of Misclassification Error in Disability Rates." *Health Economics,* vol. 23, no. 9, 2014, pp. 1084–1097.

Hall, Jean P., Catherine Ipsen, Noelle K. Kurth, Cathy Chambless, Sara McCormick, and Rebecca Goe. "Under-Representation of Certain Disability Groups by the American Community Survey (ACS)." *Disability and Health Journal,* vol. 10, no. 4, 2017, pp. 457–458.

Havercamp, Susan M., Gloria L. Krahn, Sheryl A. Larson, Glenn Fujiura, Tawara D. Goode, and Barbara L. Kornblau. "Identifying People with Intellectual and Developmental Disabilities in National Population Surveys." *Intellectual and Developmental Disabilities,* vol. 57, no. 5, 2019, pp. 376–389.

Ipsen, Catherine, Cathy Chambless, Noelle Kurth, Sara McCormick, Rebecca Goe, and Jean Hall. "Underrepresentation of Adolescents with Respiratory, Mental Health, and Developmental Disabilities Using American Community Survey (ACS) Questions." *Disability and Health Journal,* vol. 11, no. 3, 2018, pp. 447–450.

Kelfve, Susanne. "Underestimated Health Inequalities Among Older People—A Consequence of Excluding the Most Disabled and Disadvantaged." *Journals of Gerontology Series B,* vol. 74, no. 8, 2019, pp. e125–e134.

Kelfve, Susanne, Mats Thorslund, and Carin Lennartsson. "Sampling and Non-Response Bias on Health-Outcomes in Surveys of the Oldest Old." *European Journal of Ageing,* vol. 10, no. 3, 2013, pp. 237–245.

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.

Liew, Hui-Peng, and Sheena Gardner. "Exploring the Use of Paradata in Predicting Nonresponse in the Indonesian Family Life Survey." *Bulletin of Sociological Methodology,* vol. 126, no. 1, 2015, pp. 99–108.

Lysaght, Rosemary, Rachelle Kranenburg, Carolyn Armstrong, and Terry Krupa. "Participant Recruitment for Studies on Disability and Work: Challenges and Solutions." *Journal of Occupational Rehabilitation,* vol. 26, no. 2, 2016, pp. 125–140.

Mood, Laura, Dena Hassouneh, and Elizabeth McNeff. "A Conceptual Model to Promote the Retention of Women with Physical Disabilities in Research." *Public Health Nursing,* vol. 32, no. 4, 2015, pp. 368–377.

Ramke, Jacqueline, Anna Palagyi, Hannah Kuper, and Clare E. Gilbert. "Assessment of Response Bias Is Neglected in Cross-Sectional Blindness Prevalence Surveys: A Review of Recent Surveys in Low- and Middle-Income Countries." *Ophthalmic Epidemiology,* vol. 25, no. 5, 2018, pp. 379–385.

Sharp, Rebecca A., Oliver C. Mudford, and Douglas Elliffe. "Representativeness of Direct Observations Selected Using a Work-Sampling Equation." *Journal of Applied Behavior Analysis,* vol. 48, no. 1, 2015, pp. 153–166.

Siordia, Carlos, and Rebekah Young. "Methodological Note: Allocation of Disability Items in the American Community Survey." *Disability and Health Journal,* vol. 6, no. 2, 2013, pp. 149–153.

Valerio, Melissa A., Natalia Rodriguez, Paula Winkler, Jaime Lopez, Meagen Dennison, Yuanyuan Liang, and Barbara J. Turner. "Comparing Two Sampling Methods to Engage Hard-to-Reach Communities in Research Priority Setting." *BMC Medical Research Methodology,* vol. 16, no. 146, 2016, online only.

Ipsen, Catherine, Noelle Kurth, and Jean Hall. "Evaluating MTurk as a Recruitment Tool for Rural People with Disabilities." *Disability and Health Journal,* vol. 14, no. 1, 2021, article no. 100991.

Wilson, Nathan J., Yu-Wei Chen, Natasha Mahoney, Angus Buchanan, Anne Marks, and Reinie Cordier. "Experience Sampling Method and the Everyday Experiences of Adults with Intellectual Disability: A Feasibility Study." *Journal of Applied Research in Intellectual Disabilities,* vol. 33, no. 6, 2020, pp. 1328–1339.

E. Special Populations

1. Children and Youth with Disabilities

Adams, Dawn, Louise Handley, Mary Heald, Doug Simkiss, Alison Jones, Emily Walls, and Chris Oliver. "A Comparison of Two Methods for Recruiting Children with an Intellectual Disability." *Journal of Applied Research in Intellectual Disabilities,* vol. 30, no. 4, 2017, pp. 696–704.

Attell, Brandon K., Christopher Cappelli, Brigitte Manteuffel, and Hongli Li. "Measuring Functional Impairment in Children and Adolescents: Psychometric Properties of the Columbia Impairment Scale (CIS)." *Evaluation and the Health Professions,* vol. 43, no. 1, 2020, pp. 3–15.

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.

Bertills, Karin, Mats Granlund, and Lilly Augustine. "Measuring Self-Efficacy, Aptitude to Participate and Functioning in Students With and Without Impairments." *European Journal of Special Needs Education,* vol. 33, no. 4, 2018, pp. 572–583.

Bishop, Somer L., Marisela Huerta, Katherine Gotham, Karoline Alexandra Havdahl, Andrew Pickles, Amie Duncan, Vanessa Hus Bal, Lisa Croen, and Catherine Lord. "The Autism Symptom Interview, School-Age: A Brief Telephone Interview to Identify Autism Spectrum Disorders in 5-to-12-Year-Old Children." *Autism Research,* vol. 10, no. 1, 2017, pp. 78–88.

Blake, Grant A. "A New Protocol to Assess the Subjective Wellbeing of Adolescents with Intellectual Disability." *Journal of Policy and Practice in Intellectual Disabilities,* vol. 14, no. 4, 2017, pp. 298–308.

Blakeslee, Jennifer E., A. Del Quest, Jennifer Powers, Laurie E. Powers, Sarah Geenen, May Nelson, Lawrence D. Dalton, and Elizabeth McHugh. "Reaching Everyone: Promoting the Inclusion of Youth with Disabilities in Evaluating Foster Care Outcomes." *Children and Youth Services Review,* vol. 35, no. 11, 2013, pp. 1801–1808.

Boström, Petra, Jakob Å. Johnels, Maria Thorson, and Malin Broberg. "Subjective Mental Health, Peer Relations, Family, and School Environment in Adolescents with Intellectual Developmental Disorder: A First Report of a New Questionnaire Administered on Tablet PCs." *Journal of Mental Health Research in Intellectual Disabilities,* vol. 9, no. 4, 2016, pp. 207–231.

Bozzay, Melanie L., Kimberly N. O'Leary, Alessandro S. De Nadai, Kim Gryglewicz, Gabriela Romero, and Marc S. Karver. "Adolescent Depression: Differential Symptom Presentations in Deaf and Hard-of-Hearing Youth Using the Patient Health Questionnaire-9." *Journal of Deaf Studies and Deaf Education,* vol. 22, no. 2, 2017, pp. 195–203.

Brady, Geraldine, and Anita Franklin. "Challenging Dominant Notions of Participation and Protection Through a Co-Led Disabled Young Researcher Study." *Journal of Children's Services,* vol. 14, no. 3, 2019, pp. 174–185.

Broekhof, Evelien, Maartje Kouwenberg, Paul Oosterveld, Johan H. M. Frijns, and Carolien Rieffe. "Use of the Brief Shame and Guilt Questionnaire in Deaf and Hard of Hearing Children and Adolescents." *Assessment,* vol. 27, no. 1, 2020, pp. 194–205.

Bunning, Karen, Ruth Alder, Lydia Proudman, and Harriet Wyborn. "Co-Production and Pilot of a Structured Interview Using Talking Mats® to Survey the Television Viewing Habits and Preferences of Adults and Young People with Learning Disabilities." *British Journal of Learning Disabilities,* vol. 45, no. 1, 2017, pp. 1–11.

Cappa, Claudia, Daniel Mont, Mitchell Loeb, Christina Misunas, Jennifer Madans, Tijana Comic, and Filipa de Castro. "The Development and Testing of a Module on Child Functioning for Identifying Children with Disabilities on Surveys. III: Field Testing." *Disability and Health Journal,* vol. 11, no. 4, 2018, pp. 510–518.

Curtin, Carol, Linda G. Bandini, Aviva Must, Sarah Phillips, Melissa C.T. Maslin, Charmaine Lo, James M. Gleason, Richard K. Fleming, and Heidi I. Stanish. "Including Youth with Intellectual Disabilities in Health Promotion Research: Development and Reliability of a Structured Interview to Assess the Correlates of Physical Activity Among Youth." *Journal of Applied Research in Intellectual Disabilities,* vol. 29, no. 4, 2016, pp. 378–386.

Dada, Shakila, Anna K. Andersson, Adele May, Elisabeth E. Andersson, Mats Granlund, and Karina Huus. "Agreement Between Participation Ratings of Children with Intellectual Disabilities and Their Primary Caregivers." *Research in Developmental Disabilities,* vol. 104, 2020, article no. 103715.

Dekkers, Laura M.S., Anika Bexkens, Abe D. Hofman, Paul D. Boeck, Annematt L. Collot d'Escury, and Hilde M. Huizenga. "Formal Modeling of the Resistance to Peer Influence Questionnaire: A Comparison of Adolescent Boys and Girls With and Without Mild-to-Borderline Intellectual Disability." *Assessment,* vol. 26, no. 6, 2019, pp. 1070–1083.

Deroche, Chelsea B., Margaret M. Holland, Suzanne McDermott, Julie A. Royer, James W. Hardin, Joshua R. Mann, Deborah Salzberg, Orgul Ozturk, and Lijing Ouyang. "Development of a Tool to Describe Overall Health, Social Independence and Activity Limitation of Adolescents and Young Adults with Disability." *Research in Developmental Disabilities,* vol. 38, 2015, pp. 288–300.

Devandas, Catalina. "The Development and Testing of a Module on Child Functioning for Identifying Children with Disabilities in Surveys." *Disability and Health Journal,* vol. 11, no. 4, 2018, pp. 493–494.

Doherty, Sean T., Patricia McKeever, Henna Aslam, Lindsay Stephens, and Nicole Yantzi. "Use of GPS Tracking to Interactively Explore Disabled Children's Mobility and Accessibility Patterns." *Children, Youth & Environments,* vol. 24, no. 1, 2014, pp. 1-24.

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.

Ferro, Mark A., Shane W. Goodwin, Mark Sabaz, and Kathy N. Speechley. "Measurement Equivalence of the Newly Developed Quality of Life in Childhood Epilepsy Questionnaire (QOLCE-55)." *Epilepsia,* vol. 57, no. 3, 2016, pp. 427–435.

Fletcher-Watson, Sue, Kenneth Larsen, and Erica Salomone. "What Do Parents of Children with Autism Expect from Participation in Research? A Community Survey About Early Autism Studies." *Autism,* vol. 23, no. 1, 2019, pp. 175–186.

Gan, Shu-Mei, Li-Chen Tung, Chun-Yu Yeh, and Chun-Hou Wang. "ICF-CY Based Assessment Tool for Children with Autism." *Disability and Rehabilitation,* vol. 35, no. 8, 2013, pp. 678–685.

Gan, Shu-Mei, Li-Chen Tung, Chyong-Hwa Yeh, Hsiao-Yun Chang, and Chun-Hou Wang. "The ICF-CY-Based Structural Equation Model of Factors Associated with Participation in Children with Autism." *Developmental Neurorehabilitation,* vol. 17, no. 1, 2014, pp. 24–33.

Geister, Thorin L., Manjari Quintanar-Solares, Mona Martin, Stephan Aufhammer, and Friedrich Asmus. "Qualitative Development of the 'Questionnaire on Pain Caused by Spasticity (QPS),' a Pediatric Patient-Reported Outcome for Spasticity-Related Pain in Cerebral Palsy." *Quality of Life Research,* vol. 23, no. 3, 2014, pp. 887–896.

Georgiadou, Ioanna, Anastasia Vlachou, and Panayiota Stavroussi. "Development of the 'Special-Vocational-Education-Service-Quality Scale': Listening to the Voices of Students with Intellectual Disability." *Quality Assurance in Education: An International Perspective,* vol. 28, no. 2, 2020, pp. 89–103.

Ghandour, Reem M., Jessica R. Jones, Lydie A. Lebrun-Harris, Jessica Minnaert, Stephen J. Blumberg, Jason Fields, Christina Bethell, and Michael D. Kogan. "The Design and Implementation of the 2016 National Survey of Children's Health." *Maternal and Child Health Journal,* vol. 22, no. 8, 2018, pp. 1093–1102.

Gibson, Barbara E., Bhavnita Mistry, Brett Smith, Karen K. Yoshida, David Abbott, Sally Lindsay, and Yani Hamdani. "The Integrated Use of Audio Diaries, Photography, and Interviews in Research with Disabled Young Men." *International Journal of Qualitative Methods,* vol. 12, no. 1, 2013, pp. 382–402.

Gibson, Barbara E., Gillian King, Azadeh Kushki, Bhavnita Mistry, Laura Thompson, Gail Teachman, Beata Batorowicz, and Margot McMain-Klein. "A Multi-Method Approach to Studying Activity Setting Participation: Integrating Standardized Questionnaires, Qualitative Methods and Physiological Measures." *Disability and Rehabilitation,* vol. 36, no. 19, 2014, pp. 1652–1660.

Gómez, Laura E., M. L. Morán, M. Á. Alcedo, Víctor B. Arias, and Miguel-Ángel Verdugo. "Addressing Quality of Life of Children with Autism Spectrum Disorder and Intellectual Disability." *Intellectual & Developmental Disabilities,* vol. 58, no. 5, 2020, pp. 393–408.

Gonzalez, Miriam, Michelle Phoenix, Shikha Saxena, Roberta Cardoso, Michelle Canac-Marquis, Lindsay Hales, Connie Putterman, and Keiko Shikako-Thomas. "Strategies Used to Engage-Hard-to-Reach Populations in Childhood Disability Research: A Scoping Review." *Disability and Rehabilitation.* Published ahead of print, January 30, 2020.

Hall, Charlotte L., Boliang Guo, Althea Z. Valentine, Madeline J. Groom, David Daley, Kapil Sayal, and Chris Hollis. "The Validity of the Strengths and Difficulties Questionnaire (SDQ) for Children with ADHD Symptoms." *PLoS ONE,* vol. 14, no. 6, 2019, online only.

Hamilton, Sharynne, Tracy Reibel, Sarah Maslen, Rochelle Watkins, Freeman Jacinta, Hayley Passmore, Raewyn Mutch, Melissa O'Donnell, Valerie Braithwaite, and Carol Bower. "Disability 'In-Justice': The Benefits and Challenges of 'Yarning' with Young People Undergoing Diagnostic Assessment for Fetal Alcohol Spectrum Disorder in a Youth Detention Center." *Qualitative Health Research,* vol. 30, no. 2, 2020, pp. 314–327.

Hoffman, Michael F., Ivette Cejas, and Alexandra L. Quittner. "Health-Related Quality of Life Instruments for Children with Cochlear Implants: Development of Child and Parent-Proxy Measures." *Ear and Hearing,* vol. 40, no. 3, 2019, pp. 592–604.

Hornsby, Benjamin W.Y., Samantha J. Gustafson, Hope Lancaster, Sun-Joo Cho, Stephen Camarata, and Fred H. Bess. "Subjective Fatigue in Children with Hearing Loss Assessed Using Self- and Parent-Proxy Report." *American Journal of Audiology,* vol. 26, 2017, pp. 393–407.

Ipsen, Catherine, Cathy Chambless, Noelle Kurth, Sara McCormick, Rebecca Goe, and Jean Hall. "Underrepresentation of Adolescents with Respiratory, Mental Health, and Developmental Disabilities Using American Community Survey (ACS) Questions." *Disability and Health Journal,* vol. 11, no. 3, 2018, pp.447–450.

Jafari, Parvin, Seyyed J. Younesi, Ali Asgary, and Mehdi Dastjerdi Kazemi. "Pragmatic Abilities in Children with Neurodevelopmental Disorders: Development of Pragmatic Abilities Questionnaire Based on the Rasch Rating Scale Model." *Psychology Research & Behavior Management,* vol. 12, 2019, pp. 629–639.

Jenaro, Cristina, Noelia Flores, Maribel Cruz, Ma C. Pérez, Vanessa Vega, and Ví Torres. "Internet and Cell Phone Usage Patterns Among Young Adults with Intellectual Disabilities." *Journal of Applied Research in Intellectual Disabilities,* vol. 31, no. 2, 2018, pp. 259–272.

Kanagasabai, Parimala S., Brigit Mirfin-Veitch, Leigh A. Hale, and Hilda Mulligan. "A Child-Centered Method of Interviewing Children with Movement Impairments." *Physical & Occupational Therapy in Pediatrics,* vol. 38, no. 3, 2018, pp. 255–268.

Kang, Ya-Shu, Li-Yu Chen, Shaou-Gang Miaou, and Yao-Jen Chang. "A Community-Based Participatory Approach to Developing Game Technology to Provide Greater Accessibility for Children with Intellectual Disabilities." *Systemic Practice and Action Research,* 2020.

Knüppel, Ane, Gry K. Telléus, Helle Jakobsen, and Marlene B. Lauritsen. "Quality of Life in Adolescents and Adults with Autism Spectrum Disorder: Results from a Nationwide Danish Survey Using Self-Reports and Parental Proxy-Reports." *Research in Developmental Disabilities,* vol. 83, 2018, pp. 247–259.

Kramer, Jessica M., and Ariel E. Schwartz. "Development of the Pediatric Disability Inventory-Patient Reported Outcome (PEDI-PRO) Measurement Conceptual Framework and Item Candidates." *Scandinavian Journal of Occupational Therapy,* vol. 25, no. 5, 2018, pp. 335–346.

Kramer, Jessica M., Ariel E. Schwartz, Destiny Watkins, Micah Peace, Sara Luterman, Ben Barnhart, Jacob Bouma-Sims, Jessica Riley, Janet Shouse, Ravita Maharaj, Cordelia R. Rosenberg, Karyn Harvey, Juliana Huereña, Katy Schmid, and Jennifer S. Alexander. "Improving Research and Practice: Priorities for Young Adults with Intellectual/Developmental Disabilities and Mental Health Needs." *Journal of Mental Health Research in Intellectual Disabilities,* 2019, online ahead of print.

Kramer, Jessica, Yishai Barth, Katie Curtis, Kit Livingston, Madeline O'Neil, Zach Smith, Samantha Vallier, and Ashley Wolfe. "Involving Youth with Disabilities in the Development and Evaluation of a New Advocacy Training: Project TEAM." *Disability and Rehabilitation,* vol. 35, no. 7, 2013, pp. 614–622.

Krol, M., H. Sixma, J. Meerdink, H. Wiersma, and J. Rademakers. "Exploring Young Patients' Perspectives on Rehabilitation Care: Methods and Challenges of Organizing Focus Groups for Children and Adolescents." *Child: Care, Health and Development,* vol. 40, no. 4, 2014, pp. 507–514.

Liljenquist, K., W. Coster, J. Kramer, and Z. Rossetti. "Feasibility of the Participatory Experience Survey and the Setting Affordances Survey for Use in Evaluation of Programmes Serving Youth with Intellectual and Developmental Disabilities." *Child: Care, Health and Development,* vol. 43, no. 4, 2017, pp. 511–517.

Liljenquist, Kendra, Jessica Kramer, Zachary Rossetti, and Wendy Coster. "Content Development, Accessibility and Feasibility of a Self-Report Tool for Use in Programmes Serving Youth with Cognitive Disabilities: The Participatory Experience Survey." *Australian Occupational Therapy Journal,* vol. 66, no. 4, 2019, pp. 490–499.

Lloyd, Owen, Tamara Ownsworth, Jennifer Fleming, and Melanie Zimmer-Gembeck. "Development and Preliminary Validation of the Paediatric Awareness Questionnaire for Children and Adolescents with Traumatic Brain Injury." *Child Neuropsychology,* vol. 24, no. 5, 2018, pp. 702–722.

Loeb, Mitchell, Daniel Mont, Claudia Cappa, Elena De Palma, Jennifer Madans, and Roberta Crialesi. "The Development and Testing of a Module on Child Functioning for Identifying Children with Disabilities on Surveys. I: Background." *Disability and Health Journal,* vol. 11, no. 4, 2018, pp. 495–501.

Maddox, Brenna B., Luc Lecavalier, Judith S. Miller, Jill Pritchett, Jill Hollway, Susan W. White, Scott Gillespie, Andrea N. Evans, Robert T. Schultz, John D. Herrington, et al. "Reliability and Validity of the Pediatric Anxiety Rating Scale Modified for Autism Spectrum Disorder." *Autism: The International Journal of Research & Practice,* vol. 24, no. 7, 2020, pp. 1773–1782.

Markowitz, Leslie A., Charina Reyes, Rebecca A. Embacher, Leslie L. Speer, Nancy Roizen, and Thomas W. Frazier. "Development and Psychometric Evaluation of a Psychosocial Quality-of-Life Questionnaire for Individuals with Autism and Related Developmental Disorders." *Autism,* vol. 20, no. 7, 2016, pp. 832–844.

Massey, Meredith. "The Development and Testing of a Module on Child Functioning for Identifying Children with Disabilities on Surveys. II: Question Development and Pretesting." *Disability and Health Journal,* vol. 11, no. 4, 2018, pp. 502–509.

McKenzie, Karen, George Murray, Aja Murray, Rachel Martin, Yasmin Tanfield, Lauren Delahunty, Linda Hutton, Kara R. Murray, and Anne O'Hare. "Screening for Intellectual Disability with the Child and Adolescent Intellectual Screening Questionnaire: A Modified Delphi Approach." *Developmental Medicine & Child Neurology,* vol. 61, no. 8, 2019, pp. 979–983.

McKenzie, Karen, George Murray, Linda Hutton, Aja Murray, Lauren Delahunty, Anne O'Hare, and Kara Murray. "Child and Adolescent Intellectual Disability Screening Questionnaire to Identify Children with Intellectual Disability." *Developmental Medicine & Child Neurology,* vol. 61, no. 4, 2019, pp. 444–450.

Mensch, S.M., M.A. Echteld, R. Lemmens, A. Oppewal, H.M. Evenhuis, and E.A.A. Rameckers. "The Relationship Between Motor Abilities and Quality of Life in Children with Severe Multiple Disabilities." *Journal of Intellectual Disability Research,* vol. 63, no. 2, 2019, pp. 100–112.

Michel, Jeremy J., Stephanie Mayne, Robert W. Grundmeier, James P. Guevara, Nathan J. Blum, Thomas J. Power, Emily Coffin, Jeffrey M. Miller, and Alexander G. Fiks. "Sharing of ADHD Information Between Parents and Teachers Using an EHR-Linked Application." *Applied Clinical Informatics,* vol. 9, no. 4, 2018, pp. 892–904.

Milne, Rebecca, Stefanie J. Sharman, Martine B. Powell, and Sarah Mead. "Assessing the Effectiveness of the Cognitive Interview for Children with Severe Intellectual Disabilities." *International Journal of Disability, Development and Education,* vol. 60, no. 1, 2013, pp. 18–29.

Mitchell, Fraser. "Reflections on the Process of Conducting Secondary Analysis of Qualitative Data Concerning Informed Choice for Young People with a Disability in Transition." *Forum: Qualitative Social Research,* vol. 16, no. 3, 2015, pp. 1–12.

Morgan, Michelle F., Karen B. Moni, and Monica Cuskelly. "The Development of Research Skills in Young Adults with Intellectual Disability in Participatory Research." *International Journal of Disability, Development and Education,* vol. 62, no. 4, 2015, pp. 438–457.

Niemensivu, Riina, Risto P. Roine, Harri Sintonen, and Erna Kentala. "Health-Related Quality of Life in Hearing-Impaired Adolescents and Children." *Acta Oto-Laryngologica,* vol. 138, no. 7, 2018, pp. 652–658.

Nolan, Laura. "An Exploration of Proxy- and Self-Reported Adolescent Health in Low-Resource Settings." *Survey Research Methods,* vol. 10, no. 2, 2016, pp. 65–83.

O'Brien, Dai. "Visual Research with Young d/Deaf People - An Investigation of the Transitional Experiences of d/Deaf Young People from Mainstream Schools Using Auto-Driven Photo-Elicitation Interviews." *Graduate Journal of Social Science,* vol. 10, no. 2, 2013, pp. 152–175.

Pardo-Guijarro, María J., Bencie Woll, Pablo Moya-Martínez, María Martínez-Andrés, Eugenio E. Cortés-Ramírez, and Vicente Martínez-Vizcaíno. "Validity and Reliability of the Spanish Sign Language Version of the KIDSCREEN-27 Health-Related Quality of Life Questionnaire for Use in Deaf Children and Adolescents." *Gaceta Sanitaria,* vol. 27, no. 4, 2013, pp. 318–324.

Perry, Adrienne, Meisha Charles, Busi Ncube, and Jonathan Weiss. "The GO4KIDDS School Satisfaction Scale." *Journal of Applied Research in Intellectual Disabilities,* vol. 32, no. 2, 2019, pp. 471–474.

Propp, Roni, Laura McAdam, Aileen M. Davis, Nancy M. Salbach, Shannon Weir, Clarissa Encisa, and Unni G. Narayanan. "Development and Content Validation of the Muscular Dystrophy Child Health Index of Life with Disabilities Questionnaire for Children with Duchenne Muscular Dystrophy." *Developmental Medicine & Child Neurology,* vol. 61, no. 1, 2019, pp. 75–81.

Puyalto, Carol, Maria Pallisera, Judit Fullana, and Montserrat Vilà. "Doing Research Together: A Study on the Views of Advisors with Intellectual Disabilities and Non-Disabled Researchers Collaborating in Research." *Journal of Applied Research in Intellectual Disabilities,* vol. 29, no. 2, 2016, pp. 146–159.

Rice, L.J., E. Emerson, K.M. Gray, P. Howlin, B.J. Tonge, G.L. Warner, and S.L. Einfeld. "Concurrence of the Strengths and Difficulties Questionnaire and Developmental Behaviour Checklist Among Children with an Intellectual Disability." *Journal of Intellectual Disability Research,* vol. 62, no. 2, 2018, pp. 150–155.

Robinson-Cimpian, Joseph. "Inaccurate Estimation of Disparities Due to Mischievous Responders: Several Suggestions to Assess Conclusions." *Educational Researcher,* vol. 43, no. 4, 2014, pp. 171–185.

Schwartz, Ariel E., and Jessica M. Kramer. "Inclusive Approaches to Developing Content Valid Patient-Reported Outcome Measure Response Scales for Youth with Intellectual/Developmental Disabilities." *British Journal of Learning Disabilities.* Published ahead of print, October 6, 2020.

Skyrme, Sarah L., and Simon Woods. "Researching Disabled Children and Young People's Views on Decision-Making: Working Reflexively to Rethink Vulnerability." *Childhood,* vol. 25, no. 3, 2018, pp. 355–368.

Stevenson, Miriam. "Participatory Data Analysis Alongside Co-Researchers Who Have Down Syndrome." *Journal of Applied Research in Intellectual Disabilities,* vol. 27, no. 1, 2014, pp. 23–33.

Swatt, Adam J., Ariel E. Schwartz, and Jessica M. Kramer. "Youth's Perspective of Responsibility: Exploration of a Construct for Measurement with Youth with Developmental Disabilities." *Physical & Occupational Therapy in Pediatrics,* vol. 39, no. 2, 2019, pp. 204–216.

Teachman, Gail, and Barbara E. Gibson. "Children and Youth with Disabilities: Innovative Methods for Single Qualitative Interviews." *Qualitative Health Research,* vol. 23, no. 2, 2013, pp. 264–274.

Tompke, Braden K., Jennie Tang, Irina I. Oltean, M. C. Buchan, Shannon V. Reaume, and Mark A. Ferro. "Measurement Invariance of the WHODAS 2.0 Across Youth With and Without Physical or Mental Conditions." *Assessment,* vol. 27, no. 7, 2020, pp. 1490–1501.

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,* 2019.

Wager, J., F. Barth, L. Stahlschmidt, and B. Zernikow. "Testing the Validity of Telephone Interviews to Assess Chronic Pain in Children and Adolescents: A Randomized Cross-Over Trial." *European Journal of Pain,* vol.21, no. 10, 2017, pp. 1707–1716.

Warden, Clara, Katherine Yun, and Wagahta Semere. "Using the Children with Special Health Care Needs Screener with Immigrant Families: An Analysis of the National Survey of Children's Health." *Journal of Immigrant and Minority Health,* vol. 21, no. 1, 2019, pp. 189–197.

Weaver, Meaghann S., Rewais Hanna, Scott Hetzel, Karen Patterson, Alice Yuroff, Sarah Sund, Meredith Schultz, Mary Schroth, and Matthew A. Halanski. "A Prospective, Crossover Survey Study of Child- and Proxy-Reported Quality of Life According to Spinal Muscular Atrophy Type and Medical Interventions." *Journal of Child Neurology,* vol. 35, no. 5, 2020, pp. 322–330.

Wickenden, Mary, and Gayatri Kembhavi-Tam. "Ask Us too! Doing Participatory Research with Disabled Children in the Global South." *Childhood,* vol. 21, no. 3, 2014, pp. 400–417.

Wiley, Susan, and Jareen Meinzen-Derr. "Use of the Ages and Stages Questionnaire in Young Children Who Are Deaf/Hard of Hearing as a Screening for Additional Disabilities." *Early Human Development,* vol. 89, no. 5, 2013, pp. 295–300.

Wyman, Joshua D., Jennifer Lavoie, and Victoria Talwar. "Best Practices for Interviewing Children with Intellectual Disabilities in Maltreatment Cases." *Exceptionality,* vol. 27, no. 3, 2019, pp. 167–184.

2. Veterans Populations

Abraham, Traci H., Tisha L. Deen, Michelle Hamilton, Gala True, Marie T. O'Neil, Jessica Blanchard, and Madeline Uddo. "Analyzing Free-Text Survey Responses: An Accessible Strategy for Developing Patient-Centered Programs and Program Evaluation." *Evaluation and Program Planning,* vol. 78, 2020, online ahead of print.

Bovin, Michelle J., Shimrit K. Black, Paola Rodriguez, Carole A. Lunney, Sarah E. Kleiman, Frank W. Weathers, Paula P. Schnurr, James Spira, Terence M. Keane, and Brian P. Marx. "Development and Validation of a Measure of PTSD-Related Psychosocial Functional Impairment: The Inventory of Psychosocial Functioning." *Psychological Services,* vol. 15, no. 2, 2018, pp. 216–229.

Byllesby, Brianna M., Laura E. Stayton Coe, Benjamin D. Dickstein, and Kathleen M. Chard. "Psychometric Evaluation of the Brief Experiential Avoidance Questionnaire Among Treatment-Seeking Veterans with Posttraumatic Stress Disorder." *Psychological Trauma: Theory, Research, Practice, and Policy,* vol. 12, no. 7, 2020, pp. 785–789.

Clapp, Joshua D., Denise M. Sloan, William Unger, Daniel J. Lee, Janie J. Jun, Scott D. Litwack, and J.G. Beck. "Problematic Driving in Former Service Members: An Evaluation of the Driving Behavior Survey in Veterans with Posttraumatic Stress Disorder." *Journal of Anxiety Disorders,* vol. 67, 2019, online ahead of print.

Davis, Bob. "Fielding Section 508 Compliant Web Surveys for Respondents with Disabilities." Presented at the American Association for Public Opinion Research conference, New Orleans, LA, May 2017.

Dicianno, Brad E., James Joseph, Stacy Eckstein, Christina K. Zigler, Eleanor Quinby, Mark R. Schmeler, Richard M. Schein, Jon Pearlman, and Rory A. Cooper. "The Voice of the Consumer: A Survey of Veterans and Other Users of Assistive Technology." *Military Medicine,* vol. 183, no. 11-12, 2018, pp. e518–e525.

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.

Gerber, Lynn H., Ali A. Weinstein, Cara L. Frankenfeld, Minh Huynh, and Minh Huynh. "Disability Among Veterans: Analysis of the National Survey of Veterans (1997–2001)." *Military Medicine,* vol. 181, no. 3, 2016, pp. 219–226.

Mason, Lisa H., Anne L. Shandera-Ochsner, Kimberly D. Williamson, Jordan P. Harp, Maryanne Edmundson, David T.R. Berry, and Walter M. High Jr. "Accuracy of MMPI-2-RF Validity Scales for Identifying Feigned PTSD Symptoms, Random Responding, and Genuine PTSD." *Journal of Personality Assessment,* vol. 95, no. 6, 2013, pp. 585–593.

Murphy, Dominic, Mark Shevlin, Emily Pearson, Neil Greenberg, Simon Wessely, Walter Busuttil, and Thanos Karatzias. "A Validation Study of the International Trauma Questionnaire to Assess Post-Traumatic Stress Disorder in Treatment-Seeking Veterans." *The British Journal of Psychiatry,* vol. 216, no. 3, 2020, pp. 132–137.

Scott, Daniel J., J. Devin B. Watson, Thomas A. Heafner, Michael S. Clemens, Brandon W. Propper, and Zachary M. Arthurs. "Validation of the Short Musculoskeletal Function Assessment in Patients with Battlefield-Related Extremity Vascular Injuries." *Journal of Vascular Surgery,* vol. 60, no. 6, 2014, pp. 1620–1626.

Wells, Stephanie Y., Jessica R. Dietch, Benjamin J. Edner, Lisa H. Glassman, Steven R. Thorp, Leslie A. Morland, and Gregory A. Aarons. "The Development of a Brief Version of the Insomnia Severity Index (Isi-3) in Older Adult Veterans with Posttraumatic Stress Disorder." *Behavioral Sleep Medicine*. Published ahead of print, June 1, 2020.

F. Ongoing National Surveys

1. American Community Survey (ACS)

Altman, Barbara M. "Another Perspective: Capturing the Working-Age Population with Disabilities in Survey Measures." *Journal of Disability Policy Studies,* vol. 25, no. 3, 2014, pp. 146–153.

Altman, Barbara M., Jennifer Madans, and Julie D. Weeks. "An Evaluation of the American Community Survey Indicators of Disability." *Disability and Health Journal,* vol. 10, no. 4, 2017, pp. 485–491.

Altman, Barbara M., Jennifer Madans, and Julie D. Weeks. "Response Letter to J. Hall et al." *Disability and Health Journal,* vol. 10, no. 4, 2017, pp. 459–460.

Brandt, Diane E., Pei-Shu Ho, Leighton Chan, and Elizabeth K. Rasch. "Conceptualizing Disability in US National Surveys: Application of the World Health Organization's (WHO) International Classification of Functioning, Disability, and Health (ICF) Framework." *Quality of Life Research,* vol. 23, no. 10, 2014, pp. 2663–2671.

Dahlhamer, James, Julie D. Weeks, Aaron Maitland, and Jennifer H. Madans. "Conceptualizing Disability: An Evaluation of Differences Between the American Community Survey and Washington Group Short Set Questions." Paper presented at the Eleventh Conference on Health Survey Research Methods, Williamsburg, VA, March 2020. Available at https://hsrmconference.com/sites/default/files/2020/presentations/5-1_Dalhamer.pdf.

Hall, Jean P., Catherine Ipsen, Noelle K. Kurth, Cathy Chambless, Sara McCormick, and Rebecca Goe. "Under-Representation of Certain Disability Groups by the American Community Survey (ACS)." *Disability and Health Journal,* vol. 10, no. 4, 2017, pp. 457–458.

Ipsen, Catherine, Cathy Chambless, Noelle Kurth, Sara McCormick, Rebecca Goe, and Jean Hall. "Underrepresentation of Adolescents with Respiratory, Mental Health, and Developmental Disabilities Using American Community Survey (ACS) Questions." *Disability and Health Journal,* vol. 11, no. 3, 2018, pp. 447–450.

Lauer, Eric A., and Andrew J. Houtenville. "Estimates of Prevalence, Demographic Characteristics and Social Factors Among People with Disabilities in the USA: A Cross-Survey Comparison." *BMJ Open,* vol. 8, 2018, online only.

Lauer, Eric A., Megan Henly, and Rachel Coleman. "Comparing Estimates of Disability Prevalence Using Federal and International Disability Measures in National Surveillance." *Disability and Health Journal,* vol. 12, no. 2, 2019, pp. 195–202.

Livingston, Nicholas A., Tannis Hargrove, Lillie Greiman, Andrew Myers, Catherine Ipsen, and Craig Ravesloot. "An Investigation into the Temporal Scaling of Community Participation Measurement." *Rehabilitation Psychology,* vol. 60, no. 4, 2015, pp. 367–375.

Siordia, Carlos, and Rebekah Young. "Methodological Note: Allocation of Disability Items in the American Community Survey." *Disability and Health Journal,* vol. 6, no. 2, 2013, pp. 149–153.

Siordia, Carlos, Lori A. Hoepner, and Allen N. Lewis. “Why Public Health Researchers Should Consider Using Disability Data from the American Community Survey.” *Journal of Community Health,* vol. 43, no. 4, 2018, pp. 738–745.

2. Current Population Survey (CPS)

Brandt, Diane E., Pei-Shu Ho, Leighton Chan, and Elizabeth K. Rasch. “Conceptualizing Disability in US National Surveys: Application of the World Health Organization’s (WHO) International Classification of Functioning, Disability, and Health (ICF) Framework.” *Quality of Life Research,* vol. 23, no. 10, 2014, pp. 2663–2671.

Burkhauser, Richard V., Mary C. Daly, Andrew J. Houtenville, and Nigar Nargis. “Self-Reported Work-Limitation Data: What They Can and Cannot Tell Us.” *Demography,* vol. 39, no. 3, 2002, pp. 541–555.

Lauer, Eric A., and Andrew J. Houtenville. “Estimates of Prevalence, Demographic Characteristics and Social Factors Among People with Disabilities in the USA: A Cross-Survey Comparison.” *BMJ Open,* vol. 8, 2018, online only.

3. National Health Interview Survey (NHIS)

Altman, Barbara M., and Debra L. Blackwell. “Disability in U.S. Households, 2000–2010: Findings from the National Health Interview Survey.” *Family Relations,* vol. 63, no. 1, 2014, pp. 20–38.

Brandt, Diane E., Pei-Shu Ho, Leighton Chan, and Elizabeth K. Rasch. “Conceptualizing Disability in US National Surveys: Application of the World Health Organization’s (WHO) International Classification of Functioning, Disability, and Health (ICF) Framework.” *Quality of Life Research,* vol. 23, no. 10, 2014, pp. 2663–2671.

Burkhauser, Richard V., Mary C. Daly, Andrew J. Houtenville, and Nigar Nargis. “Self-Reported Work-Limitation Data: What They Can and Cannot Tell Us.” *Demography,* vol. 39, no. 3, 2002, pp. 541–555.

Hall, Jean P., Catherine Ipsen, Noelle K. Kurth, Cathy Chambless, Sara McCormick, and Rebecca Goe. “Under-Representation of Certain Disability Groups by the American Community Survey (ACS).” *Disability and Health Journal,* vol. 10, no. 4, 2017, pp. 457–458.

Havercamp, Susan M., Gloria L. Krahn, Sheryl A. Larson, Glenn Fujiura, Tawara D. Goode, and Barbara L. Kornblau. “Identifying People with Intellectual and Developmental Disabilities in National Population Surveys.” *Intellectual and Developmental Disabilities,* vol. 57, no. 5, 2019, pp. 376–389.

Lauer, Eric A., Megan Henly, and Rachel Coleman. “Comparing Estimates of Disability Prevalence Using Federal and International Disability Measures in National Surveillance.” *Disability and Health Journal,* vol. 12, no. 2, 2019, pp. 195–202.

Lauer, Eric A., and Andrew J. Houtenville. “Estimates of Prevalence, Demographic Characteristics and Social Factors Among People with Disabilities in the USA: A Cross-Survey Comparison.” *BMJ Open,* vol. 8, 2018, online only.

Stavrakantonaki, Marina, and Timothy P. Johnson. “Effects of Rosa's Law on Intellectual-Disability Reporting.” *Public Opinion Quarterly,* vol. 82, no. 3, 2018, pp. 593–604.

This page has been left blank for double sided copying.

CHAPTER III. LISTING BY AUTHOR

Abraham, Traci H., Tisha L. Deen, Michelle Hamilton, Gala True, Marie T. O'Neil, Jessica Blanchard, and Madeline Uddo. "Analyzing Free-Text Survey Responses: An Accessible Strategy for Developing Patient-Centered Programs and Program Evaluation." *Evaluation and Program Planning,* vol. 78, 2020, online ahead of print.

Adams, Dawn, Louise Handley, Mary Heald, Doug Simkiss, Alison Jones, Emily Walls, and Chris Oliver. "A Comparison of Two Methods for Recruiting Children with an Intellectual Disability." *Journal of Applied Research in Intellectual Disabilities,* vol. 30, no. 4, 2017, pp. 696–704.

Adams, M. "Results and Their Implications from Comparing Respondents and Proxy Responses for Non-Respondents with Cognitive Difficulties on a Telephone Survey." *Disability and Health Journal,* vol. 10, no. 1, 2017, pp. 131–138.

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.

AlHeresh, Rawan, Michael P. LaValley, Wendy Coster, and Julie J. Keysor. "Construct Validity and Scoring Methods of the World Health Organization: Health and Work Performance Questionnaire Among Workers with Arthritis and Rheumatological Conditions." *Journal of Occupational and Environmental Medicine,* vol. 59, no. 6, 2017, pp. e112–e118.

Altman, Barbara M. "Another Perspective: Capturing the Working-Age Population with Disabilities in Survey Measures." *Journal of Disability Policy Studies,* vol. 25, no. 3, 2014, pp. 146–153.

Altman, Barbara M., and Debra L. Blackwell. "Disability in U.S. Households, 2000–2010: Findings from the National Health Interview Survey." *Family Relations,* vol. 63, no. 1, 2014, pp. 20–38.

Altman, Barbara M., Jennifer Madans, and Julie D. Weeks. "An Evaluation of the American Community Survey Indicators of Disability." *Disability and Health Journal,* vol. 10, no. 4, 2017, pp. 485–491.

Altman, Barbara M., Jennifer Madans, and Julie D. Weeks. "Response Letter to J. Hall et al." *Disability and Health Journal,* vol. 10, no. 4, 2017, pp. 459–460.

Alvarez-Nebreda, M. Loreto, Marilyn Heng, Bernard Rosner, Michael McTague, Houman Javedan, Mitchel B. Harris, and Michael J. Weaver. "Reliability of Proxy-Reported Patient-Reported Outcomes Measurement Information System Physical Function and Pain Interference Responses for Elderly Patients with Musculoskeletal Injury." *The Journal of the American Academy of Orthopaedic Surgeons,* vol. 27, no. 4, 2019, pp. e156–e165.

Amarasinghe, Akarshani, and Prasad Wimalaratne. "An Assistive Technology Framework for Communication with Hearing Impaired Persons." *GSTF Journal on Computing,* vol. 5, no. 2, 2018, pp. 1–7.

Amspoker, Amber B., A. Lynn Snow, Brenna N. Renn, Phoebe Block, Sabrina Pickens, Robert O. Morgan, and Mark E. Kunik. "Patient Versus Informal Caregiver Proxy Reports of Pain Interference in Persons with Dementia." *Journal of Applied Gerontology.* Published ahead of print, February 6, 2020.

Arons, Alexander, Paul Krabbe, Gert Wilt, Marcel Olde Rikkert, and Eddy Adang. "Visual Analogue Scales: Scale Recalibration by Patients with Dementia and Their Proxies." *Quality of Life Research,* vol. 22, no. 5, 2013, pp. 979–986.

Arstein-Kerslake, Anna, Piers Gooding, Sarah Mercer, Marlena Raymond, and Bernadette McSherry. "Implementing a Participatory Human Rights-Based Research Methodology: The Unfitness to Plead Project." *Journal of Human Rights Practice,* vol. 11, no. 3, 2019, pp. 589–606.

Athilingam, Ponrathi, Constance Visovsky, Amanda F. Elliott, and Philip J. Rogal. "Cognitive Screening in Persons with Chronic Diseases in Primary Care: Challenges and Recommendations for Practice." *American Journal of Alzheimer's Disease and Other Dementias,* vol. 30, no. 6, 2015, pp. 547–558.

Attell, Brandon K., Christopher Cappelli, Brigitte Manteuffel, and Hongli Li. "Measuring Functional Impairment in Children and Adolescents: Psychometric Properties of the Columbia Impairment Scale (CIS)." *Evaluation and the Health Professions,* vol. 43, no. 1, 2020, pp. 3–15.

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.

Azevedo, Bruna R., Crystian B. Oliveira, Giulia M.D. Araujo, Fernanda G. Silva, Tatiana M. Damato, Rafael Z. Pinto, and Diego G.D. Christofaro. "Is There Equivalence Between the Electronic and Paper Version of the Questionnaires for Assessment of Patients with Chronic Low Back Pain?" *Spine,* 2018, online ahead of print.

Bailly, Florian, Violaine Foltz, Sylvie Rozenberg, Michael Norberg, Joelle Glemarec, Sophie Pouplin, Beatrice Banneville, Christophe Demoulin, Véronique Gaud-Listrat, Bruno Fautrel, and Laure Gossec. "Development and Validation of a Questionnaire Categorizing Behavioral Strategies in Patients with Chronic Low Back Pain." *Joint, Bone, Spine,* vol. 84, no. 6, 2017, pp. 725–731.

Baker, Ashleigh T., Julie E. Byles, Deborah J. Loxton, Deirdre McLaughlin, Anna Graves, and Annette Dobson. "Utility and Acceptability of the Modified Telephone Interview for Cognitive Status in a Longitudinal Study of Australian Women Aged 85 to 90." *Journal of the American Geriatrics Society,* vol. 61, no. 7, 2013, pp. 1217–1220.

Bakker-van Gijssel, Esther J., Peter L.B.J. Lucassen, Tim C. olde Hartman, Willem J.J. Assendelft, and Henny M.J. van Schrojenstein Lantman-de Valk. "Constructing a Health Assessment Questionnaire for People with Intellectual Disabilities: A Cognitive Interview Study." *Journal of Applied Research in Intellectual Disabilities,* 2019, online ahead of print.

Banas, Jennifer R., Susan Magasi, Kim The, and David E. Victorson. "Recruiting and Retaining People with Disabilities for Qualitative Health Research: Challenges and Solutions." *Qualitative Health Research,* vol. 29, no. 7, 2019, pp. 1056–1064.

Banks, Lena M., Sian White, Adam Biran, Jane Wilbur, Shailes Neupane, Saurav Neupane, Aditi Sharma, and Hannah Kuper. "Are Current Approaches for Measuring Access to Clean Water and Sanitation Inclusive of People with Disabilities: Comparison of Individual- and Household-Level Access Between People With and Without Disabilities in the Tanahun District of Nepal." *PLOS ONE,* vol. 14, no. 10, 2019, pp. 1–16.

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.

Barrios, Polaris, Ricardo González, Sherrie Hanna, Angela Lunde, Julie Fields, Dona Locke, and Glenn Smith. "Priority of Treatment Outcomes for Caregivers and Patients with Mild Cognitive Impairment: Preliminary Analyses." *Neurology and Therapy,* vol. 5, no. 2, 2016, pp. 183–192.

Başçiftçi, Fatih, and Ayşe Eldem. "An Interactive and Multi-Functional Refreshable Braille Device for the Visually Impaired." *Displays,* vol. 41, 2016, pp. 33–41.

Beail, Nigel, and Katie Williams. "Using Qualitative Methods in Research with People Who Have Intellectual Disabilities." *Journal of Applied Research in Intellectual Disabilities,* vol. 27, no. 2, 2014, pp. 85–96.

Bear, Todd, Howard Degenholtz, Jesse Evans, and Andrew Mrkva. "The Effects of a Pre-Notification Mailer on the Response, Productivity, and Costs Associated with a CATI Survey Among People Eligible for both Medicare and Medicaid." Presented at the American Association for Public Opinion Research conference, Denver, CO, May 2018.

Beaurivage, Daniel, Louis-Philippe Boulet, Juliet M. Foster, Peter G. Gibson, and Vanessa M. McDonald. "Validation of the Patient-Completed Asthma Knowledge Questionnaire (PAKQ)." *Journal of Asthma,* vol. 55, no. 2, 2018, pp. 169–179.

Beckmann, Helen, Matthias Augustin, Christoph Heesen, Jana Poettgen, and Christine Blome. "Benefit Evaluation in Multiple Sclerosis Relapse Treatment from the Patients' Perspective – Development and Validation of a New Questionnaire." *Multiple Sclerosis and Related Disorders,* vol. 28, 2019, pp. 256–261.

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.

Bellalou, Lucie, Naomi Downes, and Emilie Cappe. "Development and Preliminary Validation of a Depressive Symptomatology Detection Scale Among Children and Adolescents on the Autism Spectrum." *Autism*. Published ahead of print, September 21, 2020.

Bentvelzen, Adam C., John D. Crawford, Adam Theobald, Kate Maston, Melissa J. Slavin, Simone Reppermund, Kristan Kang, Katya Numbers, Henry Brodaty, Perminder Sachdev, et al. "Validation and Normative Data for the Modified Telephone Interview for Cognitive Status: The Sydney Memory and Ageinggar Study." *Journal of the American Geriatrics Society,* vol. 67, no. 10, 2019, pp. 2108–2115.

Bergmann, Michael, and Johanna Bristle. "Reading Fast, Reading Slow: The Effect of Interviewers' Speed in Reading Introductory Texts on Response Behavior." *Journal of Survey Statistics & Methodology,* vol. 8, no. 2, 2020, pp. 325–351.

Bertelli, Marco O., Annamaria Bianco, Andrea Rossi, Michele Mancini, Giampaolo La Malfa, and Ivan Brown. "Impact of Severe Intellectual Disability on Proxy Instrumental Assessment of Quality of Life." *Journal of Intellectual & Developmental Disability,* vol. 44, no. 3, 2019, pp. 272–281.

Bertills, Karin, Mats Granlund, and Lilly Augustine. "Measuring Self-Efficacy, Aptitude to Participate and Functioning in Students With and Without Impairments." *European Journal of Special Needs Education,* vol. 33, no. 4, 2018, pp. 572–583.

Beullens, Koen, Geert Loosveldt, and Caroline Vandenplas. "Interviewer Effects Among Older Respondents in the European Social Survey." *International Journal of Public Opinion Research,* vol. 31, no. 4, 2019, pp. 609–625.

Bigby, Christine, Patsie Frawley, and Paul Ramcharan. "A Collaborative Group Method of Inclusive Research." *Journal of Applied Research in Intellectual Disabilities,* vol. 27, no. 1, 2014, pp. 54–64.

Bishop, Somer L., Marisela Huerta, Katherine Gotham, Karoline Alexandra Havdahl, Andrew Pickles, Amie Duncan, Vanessa Hus Bal, Lisa Croen, and Catherine Lord. "The Autism Symptom Interview, School-Age: A Brief Telephone Interview to Identify Autism Spectrum Disorders in 5-to-12-Year-Old Children." *Autism Research,* vol. 10, no. 1, 2017, pp. 78–88.

Blake, Grant A. "A New Protocol to Assess the Subjective Wellbeing of Adolescents with Intellectual Disability." *Journal of Policy and Practice in Intellectual Disabilities,* vol. 14, no. 4, 2017, pp. 298–308.

Blakeslee, Jennifer E., A. Del Quest, Jennifer Powers, Laurie E. Powers, Sarah Geenen, May Nelson, Lawrence D. Dalton, and Elizabeth McHugh. "Reaching Everyone: Promoting the Inclusion of Youth with Disabilities in Evaluating Foster Care Outcomes." *Children and Youth Services Review,* vol. 35, no. 11, 2013, pp. 1801–1808.

Boal, A.L., C.A. Vaughan, C.S. Sims, and J.N.V. Miles. "Measurement Invariance Across Administration Mode: Examining the Posttraumatic Stress Disorder (PTSD) Checklist." *Psychological Assessment,* vol. 29, no. 1, 2017, pp. 76–86.

Bode, Liv, and Christa Scheidt-Nave. "European and Global Approaches to Survey Ageing Populations and Perspectives for Joint Approaches to Measure Age-Related Health Outcomes*." BMC Proceedings,* vol. 7, suppl. 4, 2013, online only.

Bosch-Baliarda, Marta, Olga Soler Vilageliu, and Pilar Orero. "Toward a Sign Language-Friendly Questionnaire Design." *The Journal of Deaf Studies and Deaf Education,* vol. 24, no. 4, 2019, pp. 333–345.

Boström, Petra, Jakob Å. Johnels, Maria Thorson, and Malin Broberg. "Subjective Mental Health, Peer Relations, Family, and School Environment in Adolescents with Intellectual Developmental Disorder: A First Report of a New Questionnaire Administered on Tablet PCs." *Journal of Mental Health Research in Intellectual Disabilities,* vol. 9, no. 4, 2016, pp. 207–231.

Bourke, John A., Allison Nichols-Dunsmuir, Annabel Begg, Hongfang Dong, and Philip J. Schluter. "Measuring Disability: An Agreement Study Between Two Disability Measures." *Disability and Health Journal,* 2020, article no. 100995.

Bousquet, Jean, Joao Malva, Michel Nogues, Leocadio R. Mañas, Bruno Vellas, and John Farrell. "Operational Definition of Active and Healthy Aging (AHA): The European Innovation Partnership (EIP) on AHA Reference Site Questionnaire: Montpellier October 20–21, 2014, Lisbon July 2, 2015." *Journal of the American Medical Directors Association,* vol. 16, no. 12, 2015, pp. 1020–1026.

Bovin, Michelle J., Shimrit K. Black, Paola Rodriguez, Carole A. Lunney, Sarah E. Kleiman, Frank W. Weathers, Paula P. Schnurr, James Spira, Terence M. Keane, and Brian P. Marx. "Development and Validation of a Measure of PTSD-Related Psychosocial Functional Impairment: The Inventory of Psychosocial Functioning." *Psychological Services,* vol. 15, no. 2, 2018, pp. 216–229.

Bozzay, Melanie L., Kimberly N. O'Leary, Alessandro S. De Nadai, Kim Gryglewicz, Gabriela Romero, and Marc S. Karver. "Adolescent Depression: Differential Symptom Presentations in Deaf and Hard-of-Hearing Youth Using the Patient Health Questionnaire-9." *Journal of Deaf Studies and Deaf Education,* vol. 22, no. 2, 2017, pp. 195–203.

Brady, Geraldine, and Anita Franklin. "Challenging Dominant Notions of Participation and Protection Through a Co-Led Disabled Young Researcher Study." *Journal of Children's Services,* vol. 14, no. 3, 2019, pp. 174–185.

Brandt, Diane E., Pei-Shu Ho, Leighton Chan, and Elizabeth K. Rasch. "Conceptualizing Disability in US National Surveys: Application of the World Health Organization's (WHO) International Classification of Functioning, Disability, and Health (ICF) Framework." *Quality of Life Research,* vol. 23, no. 10, 2014, pp. 2663–2671.

Brehmer-Rinderer, Barbara, Elisabeth L. Zeilinger, Ana Radaljevic, and Germain Weber. "The Vienna Frailty Questionnaire for Persons with Intellectual Disabilities—Revised." *Research in Developmental Disabilities,* vol. 34, no. 6, 2013, pp. 1958–1965.

Bright, Tess, and Danuk Pallawela. "Validated Smartphone-Based Apps for Ear and Hearing Assessments: A Review." *JMIR Rehabilitation and Assistive Technologies,* vol. 3, no. 2, 2016, online only.

Broekhof, Evelien, Maartje Kouwenberg, Paul Oosterveld, Johan H. M. Frijns, and Carolien Rieffe. "Use of the Brief Shame and Guilt Questionnaire in Deaf and Hard of Hearing Children and Adolescents." *Assessment,* vol. 27, no. 1, 2020, pp. 194–205.

Brogårdh, Christina, and Jan Lexell. "Test-Retest Reliability of the Self-Reported Impairments in Persons with Late Effects of Polio (SIPP) Rating Scale." *PM&R: The Journal of Injury, Function, and Rehabilitation,* vol. 8, no. 5, 2016, pp. 399–404.

Bruno, D., A. Slachevsky, N. Fiorentino, D. S. Rueda, G. Bruno, A. R. Tagle, L. Olavarria, P. Flores, P. Lillo, M. Roca, and T. Torralva. "Argentinian/Chilean Validation of the Spanish-Language Version of Addenbrooke's Cognitive Examination III for Diagnosing Dementia." *Neurología (English Edition),* vol. 35, no. 2, 2020, pp. 82–88.

Bukhari, Marwan, and Alison Kent. "How Rheumatologists Assess Disability in the Current Era Needs an Overhaul: Focus on the Health Assessment Questionnaire." *Rheumatology,* vol. 59, no. 2, 2020, pp. 267–268.

Bunning, Karen, Ruth Alder, Lydia Proudman, and Harriet Wyborn. "Co-Production and Pilot of a Structured Interview Using Talking Mats® to Survey the Television Viewing Habits and Preferences of Adults and Young People with Learning Disabilities." *British Journal of Learning Disabilities,* vol. 45, no. 1, 2017, pp. 1–11.

Burkhauser, Richard V., Mary C. Daly, Andrew J. Houtenville, and Nigar Nargis. "Self-Reported Work-Limitation Data: What They Can and Cannot Tell Us." *Demography,* vol. 39, no. 3, 2002, pp. 541–555.

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.

Byllesby, Brianna M., Laura E. Stayton Coe, Benjamin D. Dickstein, and Kathleen M. Chard. "Psychometric Evaluation of the Brief Experiential Avoidance Questionnaire Among Treatment-Seeking Veterans with Posttraumatic Stress Disorder." *Psychological Trauma: Theory, Research, Practice, and Policy,* vol. 12, no. 7, 2020, pp. 785–789.

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.

Caldwell, Kate. "Dyadic Interviewing: A Technique Valuing Interdependence in Interviews with Individuals with Intellectual Disabilities." *Qualitative Research,* vol. 14, no. 4, 2014, pp. 488–507.

Callahan, Ryan. "Getting the Team Ready: Training and Certifying Interviewers for a Survey of People with Disabilities." Presented at the International Field Directors and Technology conference, Denver, CO, May 2018.

Calmon Almeida, Verena, Walderi Monteiro da Silva Junior, Olaf K. de Camargo, Valter Joviniano de Santana Filho, Géssica U. Oliveira, Mylena S. Santana, and Jader Pereira de Farias Neto. "Do the Commonly Used Standard Questionnaires Measure What Is of Concern to Patients with Low Back Pain? " *Clinical Rehabilitation,* vol. 34, no. 10, 2020, pp. 1313–1324.

Campbell, Julie A., George A. Jelinek, Tracey J. Weiland, Nupur Nag, Sandra L. Neate, Andrew J. Palmer, Brendan Mulhern, Alysha De Livera, and Steve Simpson-Yap. "SF-6D Health State Utilities for Lifestyle, Sociodemographic and Clinical Characteristics of a Large International Cohort of People with Multiple Sclerosis." *Quality of Life Research: An International Journal of Quality of Life Aspects of Treatment, Care & Rehabilitation,* vol. 29, no. 9, 2020, pp. 2509–2527.

Cappa, Claudia, Daniel Mont, Mitchell Loeb, Christina Misunas, Jennifer Madans, Tijana Comic, and Filipa de Castro. "The Development and Testing of a Module on Child Functioning for Identifying Children with Disabilities on Surveys. III: Field Testing." *Disability and Health Journal,* vol. 11, no. 4, 2018, pp. 510–518.

Carvalho, Flávia A., Priscila K. Morelhão, Marcia R. Franco, Chris G. Maher, Rob J.E.M. Smeets, Crystian B. Oliveira, Ismael F. Freitas Júnior, and Rafael Z. Pinto. "Reliability and Validity of Two Multidimensional Self-Reported Physical Activity Questionnaires in People with Chronic Low Back Pain." *Musculoskeletal Science and Practice,* vol. 27, 2017, pp. 65–70.

Carvalho, Janessa O., Beth Springate, Rachel A. Bernier, and Jennifer Davis. "Psychometrics of the AAN Caregiver Driving Safety Questionnaire and Contributors to Caregiver Concern About Driving Safety in Older Adults." *International Psychogeriatrics,* vol. 30, no. 3, 2018, pp. 355–364.

Chandler, Jesse J. "Surveying Vocational Rehabilitation Applicants Online: A Feasibility Study." *Journal of Disability Policy Studies,* vol. 30, no. 3, 2019, pp. 164–173.

Chandler, Jesse. "Pilot Survey Using a Web-Based Follow Up Panel." Presented at the State-of-the-Science Conference; Rehabilitation Research and Training Center on Disability Statistics and Demographics, Washington, DC, February 2017.

Chapko, Dorota, Pino Frumiento, Nalini Edwards, Lizzie Emeh, Donald Kennedy, David McNicholas, Michaela Overton, Mark Snead, Robyn Steward, Jenny M. Sutton, et al. "'We Have Been Magnified for Years - Now You Are Under the Microscope!': Co-Researchers with Learning Disabilities Created an Online Survey to Challenge Public Understanding of Learning Disabilities." *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems,* April 2020, pp. 1–17.

Chen, Hsin-Hao, Fang-Ju Sun, Tzu-Lin Yeh, Hsueh-Erh Liu, Hsiu-Li Huang, Benjamin I. Kuo, and Hsin-Yi Huang. "The Diagnostic Accuracy of the Ascertain Dementia 8 Questionnaire for Detecting Cognitive Impairment in Primary Care in the Community, Clinics and Hospitals: A Systematic Review and Meta-Analysis." *Family Practice,* vol. 35, no. 3, 2018, pp. 239–246.

Chen, Ke-Yu, Mark Harniss, Shwetak Patel, and Kurt Johnson. "Implementing Technology-Based Embedded Assessment in the Home and Community Life of Individuals Aging with Disabilities: A Participatory Research and Development Study." *Disability and Rehabilitation: Assistive Technology,* vol. 9, no. 2, 2014, pp. 112–120.

Chiarotto, Alessandro, Carla Vanti, Christine Cedraschi, Silvano Ferrari, Fernanda de Lima e Sà Resende, Raymond W. Ostelo, and Paolo Pillastrini. "Responsiveness and Minimal Important Change of the Pain Self-Efficacy Questionnaire and Short Forms in Patients with Chronic Low Back Pain." *The Journal of Pain,* vol. 17, no. 6, 2016, pp. 707–718.

Chiarotto, Alessandro, Leo D. Roorda, Martine H. Crins, Maarten Boers, Raymond W. Ostelo, and Caroline B. Terwee. "PROMIS Physical Function Short Forms Display Item- and Scale-Level Characteristics at Least as Good as the Roland Morris Disability Questionnaire in Patients with Chronic Low Back Pain." *Archives of Physical Medicine and Rehabilitation,* 2019, online ahead of print.

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.

Cihak, David F., Donald McMahon, Cate C. Smith, Rachel Wright, and Melinda M. Gibbons. "Teaching Individuals with Intellectual Disability to Email Across Multiple Device Platforms." *Research in Developmental Disabilities,* vol. 36, 2015, pp. 645–656.

Clapp, Joshua D., Denise M. Sloan, William Unger, Daniel J. Lee, Janie J. Jun, Scott D. Litwack, and J.G. Beck. "Problematic Driving in Former Service Members: An Evaluation of the Driving Behavior Survey in Veterans with Posttraumatic Stress Disorder." *Journal of Anxiety Disorders,* vol. 67, 2019, online ahead of print.

Clark, Lauren, Marjorie A. Pett, Elizabeth M. Cardell, Jia-Wen Guo, Erin Johnson, and Jia-Wen Guo. "Developing a Health-Related Quality-of-Life Measure for People with Intellectual Disability." *Intellectual & Developmental Disabilities,* vol. 55, no. 3, 2017, pp. 140–153.

Clarke, Jason, Katherine Prescott, and Rebecca Milne. "How Effective Is the Cognitive Interview When Used with Adults with Intellectual Disabilities Specifically with Conversation Recall?" *Journal of Applied Research in Intellectual Disabilities,* vol. 26, no. 6, 2013, pp. 546–556.

Clarkson, Katrina, Lynne T. Stokes, Carol Sacchett, and Stephen Ashford. "Enabling People with Communication and Cognitive Impairments to Provide Feedback on Service Satisfaction: Development and Reliability Testing of an Adapted Pictorial Questionnaire." *International Journal of Therapy & Rehabilitation,* vol. 27, no. 7, 2020, pp. 1–15.

Contractor, Ateka A., Nicole H. Weiss, Nathan T. Kearns, Stephanie V. Caldas, and Katherine L. Dixon-Gordon. "Assessment of Posttraumatic Stress Disorder's E2 Criterion: Development, Pilot Testing, and Validation of the Posttrauma Risky Behaviors Questionnaire." *International Journal of Stress Management,* vol. 27, no. 3, 2020, pp. 292–303.

Corby, Deirdre, and Mary R. Sweeney. "Researchers' Experiences and Lessons Learned from Doing Mixed-Methods Research with a Population with Intellectual Disabilities: Insights from the SOPHIE Study." *Journal of Intellectual Disabilities,* vol. 23, no. 2, 2019, pp. 250–265.

Cridland, Elizabeth K., Lyn Phillipson, Christopher Brennan-Horley, and Kate Swaffer. "Reflections and Recommendations for Conducting In-Depth Interviews with People with Dementia." *Qualitative Health Research,* vol. 26, no. 13, 2016, pp. 1774–1786.

Cunha-Miranda, Luís, Helena Santos, Cláudia Miguel, Cândida Silva, Filipe Barcelos, Joana Borges, Ricardo Trinca, Vera Vicente, and Tiago Silva. "Validation of Portuguese-Translated Computer Touch-Screen Questionnaires in Patients with Rheumatoid Arthritis and Spondyloarthritis, Compared with Paper Formats." *Rheumatology International,* vol. 35, no. 12, 2015, pp. 2029–2035.

Curtin, Carol, Linda G. Bandini, Aviva Must, Sarah Phillips, Melissa C.T. Maslin, Charmaine Lo, James M. Gleason, Richard K. Fleming, and Heidi I. Stanish. “Including Youth with Intellectual Disabilities in Health Promotion Research: Development and Reliability of a Structured Interview to Assess the Correlates of Physical Activity Among Youth.” *Journal of Applied Research in Intellectual Disabilities,* vol. 29, no. 4, 2016, pp. 378–386.

Dada, Shakila, Anna K. Andersson, Adele May, Elisabeth E. Andersson, Mats Granlund, and Karina Huus. “Agreement Between Participation Ratings of Children with Intellectual Disabilities and Their Primary Caregivers.” *Research in Developmental Disabilities,* vol. 104, 2020, article no. 103715.

Dahlhamer, James, Julie D. Weeks, Aaron Maitland, and Jennifer H. Madans. “Conceptualizing Disability: An Evaluation of Differences Between the American Community Survey and Washington Group Short Set Questions.” Paper presented at the Eleventh Conference on Health Survey Research Methods, Williamsburg, VA, March 2020. Available at https://hsrmconference.com/sites/default/files/2020/presentations/5-1_Dalhamer.pdf.

Dahlhamer, James, Julie Weeks, and Jennifer Madans. “Examining Agreement Between Responses to Independent Sets of Disability Measures: A Comparison of the American Community Survey and Washington Group Short Set Questions.” Presented at the American Statistical Association Joint Statistical Meetings, Baltimore, MD, August 2017.

D'Amico, Domenico, Licia Grazzi, Eleonora Grignani, Matilde Leonardi, Emanuela Sansone, Alberto Raggi, Venusia Covelli, Erika Guastafierro, Chiara Scaratti, Susanna Usai, et al. “HEADWORK Questionnaire: Why Do We Need a New Tool to Assess Work-Related Disability in Patients with Migraine?” *Headache: The Journal of Head & Face Pain,* vol. 60, no. 2, 2020, pp. 497–504.

Dang, Linh, Liming Dong, and Briana Mezuk. “Shades of Blue and Gray: A Comparison of the Center for Epidemiologic Studies Depression Scale and the Composite International Diagnostic Interview for Assessment of Depression Syndrome in Later Life.” *Gerontologist,* vol. 60, no. 4, 2020, pp. e242–e253.

Daniel, Matthew R., Susan A. Sadek, and Peter E. Langdon. “The Reliabilty and Validity of a Revised Version of the How I Think Questionnaire for Men Who Have Intellectual Disabilities.” *Psychology, Crime & Law,* vol. 24, no. 4, 2018, pp. 379–390.

Davies, Katharine. “Conceptualizing Participation and Communication Disorder in Dementia Research.” *Perspectives of the ASHA Special Interest Groups,* vol. 5, no. 1, 2020, pp. 256–260.

Davis, Bob. “Fielding Section 508 Compliant Web Surveys for Respondents with Disabilities.” Presented at the American Association for Public Opinion Research conference, New Orleans, LA, May 2017.

Davis, Jennifer C., Ging-Yuek Hsiung, Stirling Bryan, Claudia Jacova, Patrizio Jacova, Michelle Munkacsy, Winnie Cheung, Philip Lee, and Teresa Liu-Ambrose. “Agreement Between Patient and Proxy Assessments of Quality of Life Among Older Adults with Vascular Cognitive Impairment Using the EQ-5D-3L and ICECAP-O.” *PLoS ONE,* vol. 11, no. 4, 2016, online only.

De Cesarei, Andrea, and Bruno Baldaro. "Doing Online Research Involving University Students with Disabilities: Methodological Issues." *Computers in Human Behavior,* vol. 53, 2015, pp. 374–380.

de Geus-Neelen, Karin C.J.M., Wietske M.W.J. van Oorsouw, Lex A.H.C. Hendriks, and Petri J.C.M. Embregts. "Perceptions of Staff and Family of the Quality of Life of People with Severe to Profound Intellectual Disability." *Journal of Intellectual & Developmental Disability,* vol. 44, no. 1, 2019, pp. 42–50.

de Guise, Elaine, Sara Bélanger, Simon Tinawi, Kirsten Anderson, Joanne LeBlanc, Julie Lamoureux, Hé Audrit, and Mitra Feyz. "Usefulness of the Rivermead Postconcussion Symptoms Questionnaire and the Trail-Making Test for Outcome Prediction in Patients with Mild Traumatic Brain Injury." *Applied Neuropsychology: Adult,* vol. 23, no. 3, 2016, pp. 213–222.

de Vries, Kay, Carol J. Leppa, Rosemarie Sandford, and Vasso Vydelingum. "Administering Questionnaires to Older People: Rigid Adherence to Protocol May Deny and Disacknowledge Emotional Expression." *Journal of Aging Studies,* vol. 31, 2014, pp. 132–138.

Dean, Katherine, Crispin Jenkinson, Gordon Wilcock, and Zuzana Walker. "The Development and Validation of a Patient-Reported Quality of Life Measure for People with Mild Cognitive Impairment." *International Psychogeriatrics,* vol. 26, no. 3, 2014, pp. 487–497.

Dean, Katherine, Zuzana Walker, and Crispin Jenkinson. "Data Quality, Floor and Ceiling Effects, and Test-Retest Reliability of the Mild Cognitive Impairment Questionnaire." *Patient Related Outcome Measures,* vol. 9, 2018, pp. 43–47.

Dee-Price, Betty-Jean M., Lorna Hallahan, Diane Nelson Bryen, and Joanne M. Watson. "Every Voice Counts: Exploring Communication Accessible Research Methods." *Disability & Society,* February 18, 2020.

Dekkers, Laura M.S., Anika Bexkens, Abe D. Hofman, Paul D. Boeck, Annematt L. Collot d'Escury, and Hilde M. Huizenga. "Formal Modeling of the Resistance to Peer Influence Questionnaire: A Comparison of Adolescent Boys and Girls With and Without Mild-to-Borderline Intellectual Disability." *Assessment,* vol. 26, no. 6, 2019, pp. 1070–1083.

Deroche, Chelsea B., Margaret M. Holland, Suzanne McDermott, Julie A. Royer, James W. Hardin, Joshua R. Mann, Deborah Salzberg, Orgul Ozturk, and Lijing Ouyang. "Development of a Tool to Describe Overall Health, Social Independence and Activity Limitation of Adolescents and Young Adults with Disability." *Research in Developmental Disabilities,* vol. 38, 2015, pp. 288–300.

Devandas, Catalina. "The Development and Testing of a Module on Child Functioning for Identifying Children with Disabilities in Surveys." *Disability and Health Journal,* vol. 11, no. 4, 2018, pp. 493–494.

Di Bari, Mauro, Francesco Profili, Stefania Bandinelli, Anna Salvioni, Enrico Mossello, Carla Corridori, Matilde Razzanelli, Teresa Di Fiandra, and Paolo Francesconi. "Screening for Frailty in Older Adults Using a Postal Questionnaire: Rationale, Methods, and Instruments Validation of the INTER-FRAIL Study." *Journal of the American Geriatrics Society,* vol. 62, no. 10, 2014, pp. 1933–1937.

Di Lorito, Claudio, Alessandro Bosco, Linda Birt, and Angela Hassiotis. "Co-research with Adults with Intellectual Disability: A Systematic Review." *Journal of Applied Research in Intellectual Disabilities,* vol. 31, no. 5, 2018, pp. 669–686.

Dicianno, Brad E., James Joseph, Stacy Eckstein, Christina K. Zigler, Eleanor Quinby, Mark R. Schmeler, Richard M. Schein, Jon Pearlman, and Rory A. Cooper. "The Voice of the Consumer: A Survey of Veterans and Other Users of Assistive Technology." *Military Medicine,* vol. 183, no. 11-12, 2018, pp. e518–e525.

Digby, Robin, Susan Lee, and Allison Williams. "Interviewing People with Dementia in Hospital: Recommendations for Researchers." *Journal of Clinical Nursing,* vol. 25, no. 7-8, 2016, pp. 1156–1165.

Dim, Nem K., Kibum Kim, and Xiangshi Ren. "Designing Motion Marking Menus for People with Visual Impairments." *International Journal of Human-Computer Studies,* vol. 109, 2018, pp. 79–88.

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.

Doherty, Sean T., Patricia McKeever, Henna Aslam, Lindsay Stephens, and Nicole Yantzi. "Use of GPS Tracking to Interactively Explore Disabled Children's Mobility and Accessibility Patterns." *Children, Youth & Environments,* vol. 24, no. 1, 2014, pp. 1–24.

Dorozenko, Kate P., Brian J. Bishop, and Lynne D. Roberts. "Fumblings and Faux Pas: Reflections on Attempting to Engage in Participatory Research with People with an Intellectual Disability." *Journal of Intellectual & Developmental Disability,* vol. 41, no. 3, 2016, pp. 197–208.

Eccles, Alicia, Reg Morris, and Ian Kneebone. "Psychometric Properties of the Behavioural Outcomes of Anxiety Questionnaire in Stroke Patients with Aphasia." *Clinical Rehabilitation,* vol. 31, no. 3, 2017, pp. 369–378.

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.

Eide, Arne H., Karin Dyrstad, Alister Munthali, Gert Van Rooy, Stine H. Braathen, Thomas Halvorsen, Frans Persendt, Peter Mvula, and Jan K. Rød. "Combining Survey Data, GIS and Qualitative Interviews in the Analysis of Health Service Access for Persons with Disabilities." *BMC International Health and Human Rights,* vol. 18, no. 26, 2018, online only.

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.

Emerson, Eric, David Felce, and Roger J. Stancliffe. “Issues Concerning Self-Report Data and Population-Based Data Sets Involving People with Intellectual Disabilities.” *Intellectual & Developmental Disabilities,* vol. 51, no. 5, 2013, pp. 333–348.

Facal, David, Miguel A.R. Carabias, Arturo X. Pereiro, Cristina Lojo-Seoane, María Campos-Magdaleno, Roos J. Jutten, Sietske A.M. Sikkes, and Onésimo Juncos-Rabadán. “Assessing Everyday Activities Across the Dementia Spectrum with the Amsterdam IADL Questionnaire.” *Current Alzheimer Research,* vol. 15, no. 13, 2018, pp. 1261–1266.

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.

Farin, Erik, Antje Ullrich, and Michaela Nagl. “Health Education Literacy in Patients with Chronic Musculoskeletal Diseases: Development of a New Questionnaire and Sociodemographic Predictors.” *Health Education Research,* vol. 28, no. 6, 2013, pp. 1080–1091.

Farin, Erik, Michaela Nagl, and Antje Ullrich. “The Comprehensibility of Health Education Programs: Questionnaire Development and Results in Patients with Chronic Musculoskeletal Diseases.” *Patient Education and Counseling,* vol. 90, no. 2, 2013, pp. 239–246.

Farina, Nicolas, Laura J. Hughes, Amber Watts, and Ruth G. Lowry. “Use of Physical Activity Questionnaires in People with Dementia: A Scoping Review.” *Journal of Aging and Physical Activity,* 2018, pp. 1–24.

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.

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 and Psychiatric Epidemiology.* Published ahead of print, September 14, 2020.

Fenwick, Eva K., Ryan E.K. Man, Gwyn Rees, Jill Keeffe, Tien Wong, Tien Y. Wong, and Ecosse L. Lamoureux. “Reducing Respondent Burden: Validation of the Brief Impact of Vision Impairment Questionnaire.” *Quality of Life Research,* vol. 26, no. 2, 2017, pp. 479–488.

Fernandes-Taylor, Sara, Cara Damico Smith, Natalia Arroyo, Kemberlee Bonnet, David Schlundt, Margarete Wichmann, Irene Feurer, and David O. Francis. “Study Protocol to Develop a Patient-Reported Outcome Measuring Disability Associated with Unilateral Vocal Fold Paralysis: A Mixed-Methods Approach with the CoPE Collaborative.” *BMJ Open,* vol. 9, 2019, online only.

Ferretti, Lisa A., and Philip McCallion. “Translating the Chronic Disease Self-Management Program for Community-Dwelling Adults with Developmental Disabilities.” *Journal of Aging & Health,* vol. 31, suppl. 10, 2019, pp. 22S–38S.

Ferro, Mark A., Shane W. Goodwin, Mark Sabaz, and Kathy N. Speechley. "Measurement Equivalence of the Newly Developed Quality of Life in Childhood Epilepsy Questionnaire (QOLCE-55)." *Epilepsia,* vol. 57, no. 3, 2016, pp. 427–435.

Finger, Robert P., Betty Tellis, Julie Crewe, Jill E. Keeffe, Lauren N. Ayton, and Robyn H. Guymer. "Developing the Impact of Vision Impairment–Very Low Vision (IVI-VLV) Questionnaire as Part of the LoVADA Protocol." *Investigative Ophthalmology & Visual Science,* vol. 55, no. 10, 2014, pp. 6150–6158.

Fletcher-Watson, Sue, Kenneth Larsen, and Erica Salomone. "What Do Parents of Children with Autism Expect from Participation in Research? A Community Survey About Early Autism Studies." *Autism,* vol. 23, no. 1, 2019, pp. 175–186.

Flynn, Samantha, Leen Vereenooghe, Richard P. Hastings, Dawn Adams, Sally-Ann Cooper, Nick Gore, Chris Hatton, Kerry Hood, Andrew Jahoda, Peter E. Langdon, Rachel McNamara, Chris Oliver, Ashok Roy, Vasiliki Totsika, and Jane Waite. "Measurement Tools for Mental Health Problems and Mental Well-Being in People with Severe or Profound Intellectual Disabilities: A Systematic Review." *Clinical Psychology Review,* vol. 57, 2017, pp. 32–44.

Formisano, Rita, Eloise Longo, Eva Azicnuda, Daniela Silvestro, Mariagrazia D'Ippolito, Jean-Luc Truelle, Lindsay Wilson, Jessica Rigon, Carmen Barba, Antonio Forcina, Marco Giustini, Nicole von Steinbüchel, and Klaus von Wild. "Quality of Life in Persons After Traumatic Brain Injury as Self-Perceived and as Perceived by the Caregivers." *Neurological Sciences,* vol. 38, no. 2, 2017, pp. 279–286.

Fox, Rina S., John D. Peipert, Montserrat Vera-Llonch, Glenn Phillips, and David Cella. "PROMIS® and Neuro-QoL™ Measures Are Valid Measures of Health-Related Quality of Life Among Patients with Familial Chylomicronemia Syndrome." *Expert Review of Cardiovascular Therapy,* vol. 18, no. 4, 2020, pp. 231–238.

Frankena, T.K., J. Naaldenberg, M. Cardol, J.V. Meijering, G. Leusink, and H.J.M. van Schrojenstein Lantman-de Valk. "Exploring Academics' Views on Designs, Methods, Characteristics and Outcomes of Inclusive Health Research with People with Intellectual Disabilities: A Modified Delphi Study." *BMJ Open,* vol. 6, no. 8, 2016, online only.

Frankena, Tessa K., Jenneken Naaldenberg, Hilde Tobi, Anneke van der Cruijsen, Henk Jansen, Henry van Schrojenstein Lantman - de Valk, Geraline Leusink, and Mieke Cardol. "A Membership Categorization Analysis of Roles, Activities and Relationships in Inclusive Research Conducted by Co-Researchers with Intellectual Disabilities." *Journal of Applied Research in Intellectual Disabilities,* vol. 32, no. 3, 2019, pp. 719–729.

Frankena, Tessa K., Jenneken Naaldenberg, Nienke Bekkema, Henny J.M. van Schrojenstein Lantman-de Valk, Mieke Cardol, and Geraline Leusink. "An Exploration of the Participation of People with Intellectual Disabilities in Research-a Structured Interview Survey." *Journal of Applied Research in Intellectual Disabilities,* vol. 31, no. 5, 2018, pp. 942–947.

Freedman, Vicki A., Frederick G. Conrad, Jennifer C. Cornman, Norbert Schwarz, and Frank P. Stafford. "Does Time Fly When You Are Having Fun? A Day Reconstruction Method Analysis." *Journal of Happiness Studies,* vol. 15, no. 3, 2014, pp. 639–655.

Frentzel, Elizabeth, Ushma Patel, and Graciela Castillo. “How Can We Develop a Survey that Everyone Can Answer? Developing and Cognitively Testing a Survey for Individuals with Physical and Mental Challenges.” Presented at the American Association for Public Opinion Research conference, Austin, TX, May 2016.

Friedman, Carli. “The Personal Outcome Measures®.” *Disability and Health Journal,* vol. 11, no. 3, 2018, pp. 351–358.

Frielink, Noud, and Petri Embregts. “Modification of Motivational Interviewing for Use with People with Mild Intellectual Disability and Challenging Behaviour.” *Journal of Intellectual & Developmental Disability,* vol. 38, no. 4, 2013, pp. 279–291.

Gaertner, Beate, Ina Seitz, Judith Fuchs, Markus A. Busch, Martin Holzhausen, Peter Martus, and Christa Scheidt-Nave. “Baseline Participation in a Health Examination Survey of the Population 65 Years and Older: Who Is Missed and Why?” *BMC Geriatrics,* vol. 16, no. 21, 2016, online only.

Galindo-Garre, Francisca, María D. Hidalgo, Georgina Guilera, Oscar Pino, J. Emilio Rojo, and Juana Gómez-Benito. “Modeling the World Health Organization Disability Assessment Schedule II Using Non-Parametric Item Response Models.” *International Journal of Methods in Psychiatric Research,* vol. 24, no. 1, 2015, pp. 1–10.

Gan, Shu-Mei, Li-Chen Tung, Chun-Yu Yeh, and Chun-Hou Wang. “ICF-CY Based Assessment Tool for Children with Autism.” *Disability and Rehabilitation,* vol. 35, no. 8, 2013, pp. 678–685.

Gan, Shu-Mei, Li-Chen Tung, Chyong-Hwa Yeh, Hsiao-Yun Chang, and Chun-Hou Wang. “The ICF-CY-Based Structural Equation Model of Factors Associated with Participation in Children with Autism.” *Developmental Neurorehabilitation,* vol. 17, no. 1, 2014, pp. 24–33.

Gardner, Raquel C., Ernesto Rivera, Megan O'Grady, Colin Doherty, Kristine Yaffe, John D. Corrigan, Jennifer Bogner, Joel Kramer, Fiona Wilson, Rudy Castellani, et al. “Screening for Lifetime History of Traumatic Brain Injury Among Older American and Irish Adults at Risk for Dementia: Development and Validation of a Web-Based Survey.” *Journal of Alzheimer's Disease,* vol. 74, no. 2, 2020, pp. 699–711.

Gaskin, Cadeyrn J., Sylvie D. Lambert, Steven J. Bowe, and Liliana Orellana. “Why Sample Selection Matters in Exploratory Factor Analysis: Implications for the 12-Item World Health Organization Disability Assessment Schedule 2.0.” *BMC Medical Research Methodology,* vol. 17, no. 40, 2017, online only.

Gather, Jakov, Janice Kalagi, Ina Otte, and Georg Juckel. “Interviewing a Person with Bipolar Disorder Under Involuntary Commitment: A Case Report.” *Journal of Empirical Research on Human Research Ethics,* vol. 14, no. 5, 2019, pp. 472–474.

Geier, Timothy J., Joshua C. Hunt, Jessica L. Hanson, Katelyn Heyrman, Sadie E. Larsen, Karen J. Brasel, Terri A. deRoon-Cassini, and Terri deRoon-Cassini. “Validation of Abbreviated Four- and Eight-Item Versions of the PTSD Checklist for DSM-5 in a Traumatically Injured Sample.” *Journal of Traumatic Stress,* vol. 33, no. 3, 2020, pp. 218–226.

Geister, Thorin L., Manjari Quintanar-Solares, Mona Martin, Stephan Aufhammer, and Friedrich Asmus. "Qualitative Development of the 'Questionnaire on Pain Caused by Spasticity (QPS),' a Pediatric Patient-Reported Outcome for Spasticity-Related Pain in Cerebral Palsy." *Quality of Life Research,* vol. 23, no. 3, 2014, pp. 887–896.

Georgiadou, Ioanna, Anastasia Vlachou, and Panayiota Stavroussi. "Development of the 'Special-Vocational-Education-Service-Quality Scale': Listening to the Voices of Students with Intellectual Disability." *Quality Assurance in Education: An International Perspective,* vol. 28, no. 2, 2020, pp. 89–103.

Gerber, Lynn H., Ali A. Weinstein, Cara L. Frankenfeld, Minh Huynh, and Minh Huynh. "Disability Among Veterans: Analysis of the National Survey of Veterans (1997–2001)." *Military Medicine,* vol. 181, no. 3, 2016, pp. 219–226.

Ghandour, Reem M., Jessica R. Jones, Lydie A. Lebrun-Harris, Jessica Minnaert, Stephen J. Blumberg, Jason Fields, Christina Bethell, and Michael D. Kogan. "The Design and Implementation of the 2016 National Survey of Children's Health." *Maternal and Child Health Journal,* vol. 22, no. 8, 2018, pp. 1093–1102.

Giambelluca, Eliana, Monica Panigazzi, Abdo Saade, and Marcello Imbriani. "Assessment of Functional Status and Rehabilitative Strategies in Occupational Therapy: Role of the Groningen Activity Restriction Questionnaire." *Giornale Italiano di Medicina del Lavoro ed Ergonomia,* vol. 41, no. 1, 2019, pp. 52–57.

Gibson, Barbara E., Bhavnita Mistry, Brett Smith, Karen K. Yoshida, David Abbott, Sally Lindsay, and Yani Hamdani. "The Integrated Use of Audio Diaries, Photography, and Interviews in Research with Disabled Young Men." *International Journal of Qualitative Methods,* vol. 12, no. 1, 2013, pp. 382–402.

Gibson, Barbara E., Gillian King, Azadeh Kushki, Bhavnita Mistry, Laura Thompson, Gail Teachman, Beata Batorowicz, and Margot McMain-Klein. "A Multi-Method Approach to Studying Activity Setting Participation: Integrating Standardized Questionnaires, Qualitative Methods and Physiological Measures." *Disability and Rehabilitation,* vol. 36, no. 19, 2014, pp. 1652–1660.

Girard, V., A. Tinland, J.P. Bonin, F. Olive, J. Poule, C. Lancon, T. Apostolidis, M. Rowe, T. Greacen, and M.C. Simeoni. "Relevance of a Subjective Quality of Life Questionnaire for Long-Term Homeless Persons with Schizophrenia." *BMC Psychiatry,* vol. 17, no. 72, 2017, online only.

Gleeson, Michael, Catherine Sherrington, Serigne Lo, Robin Auld, and Lisa Keay. "Impact of the Alexander Technique on Well-Being: A Randomised Controlled Trial Involving Older Adults with Visual Impairment." *Clinical and Experimental Optometry,* vol. 100, no. 6, 2017, pp. 633–641.

Goegan, Lauren D., Amanda I. Radil, and Lia M. Daniels. "Accessibility in Questionnaire Research: Integrating Universal Design to Increase the Participation of Individuals with Learning Disabilities." *Learning Disabilities,* vol. 16, no. 2, 2019, pp. 177–190.

Gómez, Laura E., M. L. Morán, M. Á. Alcedo, Víctor B. Arias, and Miguel-Ángel Verdugo. "Addressing Quality of Life of Children with Autism Spectrum Disorder and Intellectual Disability." *Intellectual & Developmental Disabilities,* vol. 58, no. 5, 2020, pp. 393–408.

Gomez-Gallego, M., J. Gomez-Garcia, and E. Ato-Lozano. "Addressing the Bias Problem in the Assessment of the Quality of Life of Patients with Dementia: Determinants of the Accuracy and Precision of the Proxy Ratings." *The Journal of Nutrition, Health & Aging,* vol. 19, no. 3, 2015, pp. 365–372.

Gonzalez, Miriam, Michelle Phoenix, Shikha Saxena, Roberta Cardoso, Michelle Canac-Marquis, Lindsay Hales, Connie Putterman, and Keiko Shikako-Thomas. "Strategies Used to Engage-Hard-to-Reach Populations in Childhood Disability Research: A Scoping Review." *Disability and Rehabilitation.* Published ahead of print, January 30, 2020.

Gordon, Mark F., William R. Lenderking, Amy Duhig, Julie Chandler, J. Jason Lundy, David S. Miller, Elisabeth Piault-Louis, Rachelle S. Doody, Douglas Galasko, Serge Gauthier, and Lori Frank. "Development of a Patient-Reported Outcome Instrument to Assess Complex Activities of Daily Living and Interpersonal Functioning in Persons with Mild Cognitive Impairment: The Qualitative Research Phase." *Alzheimer's & Dementia,* vol. 12, no. 1, 2016, pp. 75–84.

Gosling, Amanda, and Eirini-Christina Saloniki. "Correction of Misclassification Error in Disability Rates." *Health Economics,* vol. 23, no. 9, 2014, pp. 1084–1097.

Goujon, Nicolas, Alexandra Devine, Sally M. Baker, Beth Sprunt, Tanya J. Edmonds, Jennifer K. Booth, and Jill E. Keeffe. "A Comparative Review of Measurement Instruments to Inform and Evaluate Effectiveness of Disability Inclusive Development." *Disability and Rehabilitation,* vol. 36, no. 10, 2014, pp. 804–812.

Grau, Eric, and Jason Markesich. "Exploring Proxy Response Bias in a Large-Scale Survey of People with Disabilities." Paper presented at the Eleventh Conference on Health Survey Research Methods, Williamsburg, VA, March 2020.

Grau, Eric. "Do In-Person Interviews Reduce Bias in a Mixed-Mode Survey of Persons with Disabilities?" *Survey Practice,* vol. 7, no. 2, 2014, online only.

Green, Jane, Chloe Tolley, Sarah Bentley, Rob Arbuckle, Marie Burstedt, James Whelan, Karen Holopigian, Kali Stasi, Brigitte Sloesen, Claudio Spera, et al. "Qualitative Interviews to Better Understand the Patient Experience and Evaluate Patient-Reported Outcomes (PRO) in RLBP1 Retinitis Pigmentosa (RLBP1 RP)." *Advances in Therapy,* vol. 37, no. 6, 2020, pp. 2884–2901.

Gregersen, Merete, Mette M. Jordansen, and Debby L. Gerritsen. "Overall Quality of Life (OQoL) Questionnaire in Frail Elderly: A Study of Reproducibility and Responsiveness of the Depression List (DL)." *Archives of Gerontology and Geriatrics,* vol. 60, no. 1, 2015, pp. 22–27.

Gruters, Angélique A.A., Inez H.G.B. Ramakers, Frans R.J. Verhey, Sebastian Köhler, Roy P.C. Kessels, Marjolein E. de Vugt, and Katherine Gifford. "Association Between Proxy- or Self-Reported Cognitive Decline and Cognitive Performance in Memory Clinic Visitors." *Journal of Alzheimer's Disease,* vol. 70, no. 4, 2019, pp. 1225–1239.

Guilera, Georgina, Juana Gómez-Benito, Óscar Pino, Emilio Rojo, Eduard Vieta, Manuel J. Cuesta, Scot E. Purdon, Miguel Bernardo, Benedicto Crespo-Facorro, Manuel Franco, Anabel Martínez-Arán, Gemma Safont, Rafael Tabarés-Seisdedos, and Javier Rejas. "Disability in Bipolar I Disorder: The 36-Item World Health Organization Disability Assessment Schedule 2.0." *Journal of Affective Disorders,* vol. 174, 2015, pp. 353–360.

Guillot-Valdés, María, Alejandro Guillén-Riquelme, and Gualberto Buela-Casal. "Reliability and Validity of the Basic Depression Questionnaire." *International Journal of Clinical and Health Psychology,* vol. 19, no. 3, 2019, pp. 243–250.

Györi, Eva, Christopher Przestrzelski, Igor Pona, Michael Hagmann, Thomas Rath, Christine Radtke, and C.-H. John Tzou. "Quality of Life and Functional Assessment of Facial Palsy Patients: A Questionnaire Study." *International Journal of Surgery,* vol. 55, 2018, pp. 92–97.

Hall, Charlotte L., Boliang Guo, Althea Z. Valentine, Madeline J. Groom, David Daley, Kapil Sayal, and Chris Hollis. "The Validity of the Strengths and Difficulties Questionnaire (SDQ) for Children with ADHD Symptoms." *PLoS ONE,* vol. 14, no. 6, 2019, online only.

Hall, Jean P., Catherine Ipsen, Noelle K. Kurth, Cathy Chambless, Sara McCormick, and Rebecca Goe. "Under-Representation of Certain Disability Groups by the American Community Survey (ACS)." *Disability and Health Journal,* vol. 10, no. 4, 2017, pp. 457–458.

Hall, Natalie, Marie-Anne Durand, and Silvana E. Mengoni. "'...their Opinions Mean Something': Care Staff's Attitudes to Health Research Involving People with Intellectual Disabilities." *British Journal of Learning Disabilities,* vol. 45, no. 3, 2017, pp. 198–207.

Hamilton, Sharynne, Tracy Reibel, Sarah Maslen, Rochelle Watkins, Freeman Jacinta, Hayley Passmore, Raewyn Mutch, Melissa O'Donnell, Valerie Braithwaite, and Carol Bower. "Disability 'In-Justice': The Benefits and Challenges of 'Yarning' with Young People Undergoing Diagnostic Assessment for Fetal Alcohol Spectrum Disorder in a Youth Detention Center." *Qualitative Health Research,* vol. 30, no. 2, 2020, pp. 314–327.

Hammond, Alison, Yeliz Prior, Mike C. Horton, Alan Tennant, and Sarah Tyson. "The Psychometric Properties of the Evaluation of Daily Activity Questionnaire in Seven Musculoskeletal Conditions." *Disability and Rehabilitation,* vol. 40, no. 17, 2018, pp. 2070–2080.

Hart, Sarah M., Mikayla Pascucci, Sheetal Sood, and Emily M. Barrett. "Value, Vulnerability and Voice: An Integrative Review on Research Assent." *British Journal of Learning Disabilities,* vol. 48, no. 2, 2020, pp. 154–161.

Havercamp, Susan M., Gloria L. Krahn, Sheryl A. Larson, Glenn Fujiura, Tawara D. Goode, and Barbara L. Kornblau. "Identifying People with Intellectual and Developmental Disabilities in National Population Surveys." *Intellectual and Developmental Disabilities,* vol. 57, no. 5, 2019, pp. 376–389.

Heffernan, Eithne, David W. Maidment, Johanna G. Barry, and Melanie A. Ferguson. "Refinement and Validation of the Social Participation Restrictions Questionnaire: An Application of Rasch Analysis and Traditional Psychometric Analysis Techniques." *Ear and Hearing,* vol. 40, no. 2, 2019, pp. 328–339.

Heffernan, Eithne, Neil S. Coulson, and Melanie A. Ferguson. "Development of the Social Participation Restrictions Questionnaire (SPaRQ) Through Consultation with Adults with Hearing Loss, Researchers, and Clinicians: A Content Evaluation Study." *International Journal of Audiology,* vol. 57, no. 10, 2018, pp. 791–799.

Heffron, Jenna L., Natasha A. Spassiani, Amber M. Angell, and Joy Hammel. "Using Photovoice as a Participatory Method to Identify and Strategize Community Participation with People with Intellectual and Developmental Disabilities." *Scandinavian Journal of Occupational Therapy,* vol. 25, no. 5, 2018, pp. 382–395.

Hendriks, A.A. Jolijn, Sarah C. Smith, Theopisti Chrysanthaki, and Nick Black. "Reliability and Validity of a Self-Administration Version of DEMQOL-Proxy." *International Journal of Geriatric Psychiatry,* vol. 32, no. 7, 2017, pp. 734–741.

Henry, J.C. "Comment: Be Careful What You Ask When Interviewing Patients with Epilepsy." *Neurology,* vol. 85, no. 7, 2015, pp. 594.

Ho, Lily Y. W., Kenny C. W. Chin, Connie Y. Y. Fung, and Claudia K. Y. Lai. "Validation of the Chinese Non-pharmacological Therapy Experience Scale in Persons with Intellectual Disability." *Nursing Open,* vol. 7, no. 1, 2020, pp. 390–397.

Hoffman, Michael F., Ivette Cejas, and Alexandra L. Quittner. "Health-Related Quality of Life Instruments for Children with Cochlear Implants: Development of Child and Parent-Proxy Measures." *Ear and Hearing,* vol. 40, no. 3, 2019, pp. 592–604.

Hollinrake, Sue, Sara Spencer, and Geof Dix. "Disabled Citizens as Researchers – Challenges and Benefits of Collaboration for Effective Action and Change." *European Journal of Social Work,* vol. 22, no. 5, 2019, pp. 749–762.

Hollomotz, Andrea. "Successful Interviews with People with Intellectual Disability." *Qualitative Research,* vol. 18, no. 2, 2018, pp. 153–170.

Honkavaara, Niklas, Amer N. Al-Ani, Pierre Campenfeldt, Wilhelmina Ekström, and Margareta Hedström. "Good Responsiveness with EuroQol 5-Dimension Questionnaire and Short Form (36) Health Survey in 20–69 Years Old Patients with a Femoral Neck Fracture: A 2-Year Prospective Follow-Up Study in 182 Patients." *Injury,* vol. 47, no. 8, 2016, pp. 1692–1697.

Hornsby, Benjamin W.Y., Samantha J. Gustafson, Hope Lancaster, Sun-Joo Cho, Stephen Camarata, and Fred H. Bess. "Subjective Fatigue in Children with Hearing Loss Assessed Using Self- and Parent-Proxy Report." *American Journal of Audiology,* vol. 26, 2017, pp. 393–407.

Houtenville, Andrew, and Eric Lauer. "Comparing Prevalence Estimates for People with Disabilities in National Surveys: 2009—2014." Presented at the American Statistical Association Joint Statistical Meetings, Chicago, IL, August 2016.

Hughes, Rosemary B., Susan Robinson-Whelen, Rebecca Goe, Michelle Schwartz, Lisa Cesal, Kimberly B. Garner, Katie Arnold, Tina Hunt, and Katherine E. McDonald. "'I Really Want People to Use Our Work to Be Safe'…Using Participatory Research to Develop a Safety Intervention for Adults with Intellectual Disability." *Journal of Intellectual Disabilities,* vol. 24, no. 3, 2020, pp. 309–325.

Hunting Pompon, Rebecca, Dagmar Amtmann, Charles Bombardier, and Diane Kendall. "Modifying and Validating a Measure of Chronic Stress for People with Aphasia." *Journal of Speech, Language, and Hearing Research,* vol. 61, no. 12, 2018, pp. 2934–2949.

Iezzoni, Lisa I., Holly Matulewicz, Sarah A. Marsella, Kimberley S. Warsett, Dennis Heaphy, and Karen Donelan. "Collaborative Design of a Health Care Experience Survey for Persons with Disability." *Disability and Health Journal*, vol. 10, no. 2, 2017, pp. 231–239.

Iorio-Morin, Christian, Vanessa K. Noonan, Barry White, Luc Noreau, Jean Leblond, Frédéric S. Dumont, Brian K. Kwon, Marcel F. Dvorak, and Nicolas Dea. "Quality of Life and Health Utility Scores Among Canadians Living with Traumatic Spinal Cord Injury – A National Cross-Sectional Study." *Spine,* vol. 43, no. 14, 2018, pp. 999–1006.

Ipsen, Catherine, Cathy Chambless, Noelle Kurth, Sara McCormick, Rebecca Goe, and Jean Hall. "Underrepresentation of Adolescents with Respiratory, Mental Health, and Developmental Disabilities Using American Community Survey (ACS) Questions." *Disability and Health Journal,* vol. 11, no. 3, 2018, pp. 447–450.

Ipsen, Catherine, Noelle Kurth, and Jean Hall. "Evaluating MTurk as a Recruitment Tool for Rural People with Disabilities." *Disability and Health Journal,* vol. 14, no. 1, 2021, article no. 100991.

Iturregui-Gallardo, Gonzalo, and Jorge L. Méndez-Ulrich. "Towards the Creation of a Tactile Version of the Self-Assessment Manikin (T-SAM) for the Emotional Assessment of Visually Impaired People." *International Journal of Disability, Development and Education,* vol. 67, no. 6, 2020, pp. 657–674.

Iwanaga, Kanako, John Blake, Rana Yaghmaian, Emre Umucu, Fong Chan, Jessica M. Brooks, Maryam Rahimi, and Timothy N. Tansey. "Preliminary Validation of a Short-Form Version of the Attachment Style Questionnaire for Use in Clinical Rehabilitation Counseling Research and Practice." *Rehabilitation Counseling Bulletin,* vol. 61, no. 4, 2018, pp. 205–216.

Jafari, Parvin, Seyyed J. Younesi, Ali Asgary, and Mehdi Dastjerdi Kazemi. "Pragmatic Abilities in Children with Neurodevelopmental Disorders: Development of Pragmatic Abilities Questionnaire Based on the Rasch Rating Scale Model." *Psychology Research and Behavior Management,* vol. 12, 2019, pp. 629–639.

Jahagirdar, Deepa, Thilo Kroll, Karen Ritchie, and Sally Wyke. "Patient-Reported Outcome Measures for Chronic Obstructive Pulmonary Disease: The Exclusion of People with Low Literacy Skills and Learning Disabilities." *The Patient,* vol. 6, no. 1, 2013, pp. 11–21.

Jakobsson, Elin, Louise Nygård, Anders Kottorp, Cecilia B. Olsson, and Camilla Malinowsky. "The Use of Everyday Technology: A Comparison of Older Persons with Cognitive Impairments' Self-Reports and their Proxies' Reports." *British Journal of Occupational Therapy,* 2020.

Jayes, Mark J., and Rebecca L. Palmer. "Stroke Research Staff's Experiences of Seeking Consent from People with Communication Difficulties: Results of a National Online Survey." *Topics in Stroke Rehabilitation,* vol. 21, no. 5, 2014, pp. 443–451.

Jeannis, H., M. Goldberg, K. Seelman, M. Schmeler, and R. A. Cooper. "Participation in Science and Engineering Laboratories for Students with Physical Disabilities: Survey Development and Psychometrics." *Disability & Rehabilitation: Assistive Technology,* vol. 14, no. 7, 2019, pp. 692–709.

Jenaro, Cristina, Noelia Flores, Maribel Cruz, Ma C. Pérez, Vanessa Vega, and Ví Torres. "Internet and Cell Phone Usage Patterns Among Young Adults with Intellectual Disabilities." *Journal of Applied Research in Intellectual Disabilities,* vol. 31, no. 2, 2018, pp. 259–272.

Jen-Yi, Li, Malathy Krishnasamy, and Chen Der-Thanq. "Research with Persons with Intellectual Disabilities: An Inclusive Adaptation of Tourangeau's Model." *Alter,* vol. 9, no. 4, 2015, pp. 304–316.

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.

Jeter, Pamela E., Collin Rozanski, Robert Massof, Olukemi Adeyemo, and Gislin Dagnelie. "Development of the Ultra-Low Vision Visual Functioning Questionnaire (ULV-VFQ)." *Translational Vision Science & Technology,* vol. 6, no. 3, 2017, online only.

Johnson, Amy, Ryan Callahan, Jesse Chandler, and Jason Markesich. "Using Behavioral Science to Improve Survey Response: An Experiment with the National Beneficiary Survey." In Focus Brief. Washington, DC: Mathematica Policy Research, December 2017.

Jongsma, Karin, Julia Perry, Silke Schicktanz, and Katrin Radenbach. "Motivations for People with Cognitive Impairment to Complete an Advance Research Directive – A Qualitative Interview Study." *BMC Psychiatry,* vol. 20, no. 1, 2020, pp. 1–9.

Kaley, Alexandra, Chris Hatton, and Christine Milligan. "More than Words: The Use of Video in Ethnographic Research with People with Intellectual Disabilities." *Qualitative Health Research,* vol. 29, no. 7, 2019, pp. 931–943.

Kalpakjian, Claire Z., Jodi M. Kreschmer, Mary D. Slavin, Pamela A. Kisala, Elisabeth H. Quint, Nancy D. Chiaravalloti, Natalie Jenkins, Tamara Bushnik, Dagmar Amtmann, David S. Tulsky, et al. "Reproductive Health in Women with Physical Disability: A Conceptual Framework for the Development of New Patient-Reported Outcome Measures." *Journal of Women's Health,* vol. 29, no. 11, 2020, pp. 1427–1436.

Kanagasabai, Parimala S., Brigit Mirfin-Veitch, Leigh A. Hale, and Hilda Mulligan. "A Child-Centered Method of Interviewing Children with Movement Impairments." *Physical & Occupational Therapy in Pediatrics,* vol. 38, no. 3, 2018, pp. 255–268.

Kang, Ya-Shu, Li-Yu Chen, Shaou-Gang Miaou, and Yao-Jen Chang. "A Community-Based Participatory Approach to Developing Game Technology to Provide Greater Accessibility for Children with Intellectual Disabilities." *Systemic Practice and Action Research,* 2020.

Katzan, Irene L., Nicolas R. Thompson, Steven Z. George, Sandi Passek, Frederick Frost, and Mary Stilphen. "The Use of STarT Back Screening Tool to Predict Functional Disability Outcomes in Patients Receiving Physical Therapy for Low Back Pain." *The Spine Journal,* vol. 19, no. 4, 2019, pp. 645–654.

Kaur, Herminder, Paula Saukko, and Karen Lumsden. "Rhythms of Moving in and Between Digital Media: A Study on Video Diaries of Young People with Physical Disabilities." *Mobilities,* vol. 13, no. 3, 2018, pp. 397–410.

Kawata, Ariane K., Asha Hareendran, Shannon Shaffer, Sally Mannix, Andrew Thach, Pooja Desai, Daniel D. Mikol, Brian Ortmeier, Martha Bayliss, and Dawn C. Buse. "Evaluating the Psychometric Properties of the Migraine Functional Impact Questionnaire (MFIQ)." *Headache: The Journal of Head & Face Pain,* vol. 59, no. 8, 2019, pp. 1253–1269.

Kelfve, Susanne, Mats Thorslund, and Carin Lennartsson. "Sampling and Non-Response Bias on Health-Outcomes in Surveys of the Oldest Old." *European Journal of Ageing,* vol. 10, no. 3, 2013, pp. 237–245.

Kelfve, Susanne. "Underestimated Health Inequalities Among Older People—A Consequence of Excluding the Most Disabled and Disadvantaged." *Journals of Gerontology Series B,* vol. 74, no. 8, 2019, pp. e125–e134.

Kelly-Corless, Laura. "Delving in the Unknown: An Experience of Doing Research with d/Deaf Prisoners." *Qualitative Inquiry,* vol. 26, no. 3, 2020, pp. 355–368.

Khan, Yasmeen, Dana Lawrence, Robert Vining, and Dustin Derby. "Measuring Biopsychosocial Risk for Back Pain Disability in Chiropractic Patients Using the STarT Back Screening Tool: A Cross-Sectional Survey." *Chiropractic & Manual Therapies,* vol. 27, no. 2, 2019, 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 from Claims Data." *BMC Health Services Research,* vol. 18, no. 1, 2018, online only.

Knüppel, Ane, Gry K. Telléus, Helle Jakobsen, and Marlene B. Lauritsen. "Quality of Life in Adolescents and Adults with Autism Spectrum Disorder: Results from a Nationwide Danish Survey Using Self-Reports and Parental Proxy-Reports." *Research in Developmental Disabilities,* vol. 83, 2018, pp. 247–259.

Kocman, A., and G. Weber. "Concepts of Job Satisfaction in People with Intellectual Disability." *Journal of Intellectual Disability Research,* vol. 62, no. 9, 2018, pp. 814–819.

Koolhaas, Chantal M., Frank J. van Rooij, Magda Cepeda, Henning Tiemeier, Oscar H. Franco, and Josje D. Schoufour. "Physical Activity Derived from Questionnaires and Wrist-Worn Accelerometers: Comparability and the Role of Demographic, Lifestyle, and Health Factors Among a Population-Based Sample of Older Adults." *Clinical Epidemiology,* vol. 10, 2017, pp. 1–16.

Kotwal, Ashwin A., Philip Schumm, David W. Kern, Martha K. McClintock, Linda J. Waite, Joseph W. Shega, Megan J. Huisingh-Scheetz, and William Dale. "Evaluation of a Brief Survey Instrument for Assessing Subtle Differences in Cognitive Function Among Older Adults." *Alzheimer Disease and Associated Disorders,* vol. 29, no. 4, 2015, pp. 317–324.

Kovac, Martha, Stacie Feldman, Michael Levere, Jason Markesich and Karen CyBulski. “Offering a Web Mode for People with Disabilities: Descriptive Findings from the POD Follow Up Survey.” Paper presented at the Eleventh Conference on Health Survey Research Methods, Williamsburg, VA, March 2020. Available at https://hsrmconference.com/sites/default/files/2020/presentations/1-3_Kovac.pdf.

Kozlowski, Allan J., Ritika Singh, David Victorson, Ana Miskovic, Jin-Shei Lai, Richard L. Harvey, David Cella, and Allen W. Heinemann. “Agreement Between Responses from Community-Dwelling Persons with Stroke and Their Proxies on the NIH Neurological Quality of Life (Neuro-QoL) Short Forms.” *Archives of Physical Medicine and Rehabilitation,* vol. 96, no. 11, 2015, pp. 1986–1992.

Kramer, Jessica M., and Ariel E. Schwartz. “Development of the Pediatric Disability Inventory-Patient Reported Outcome (PEDI-PRO) Measurement Conceptual Framework and Item Candidates.” *Scandinavian Journal of Occupational Therapy,* vol. 25, no. 5, 2018, pp. 335–346.

Kramer, Jessica M., Ariel E. Schwartz, Destiny Watkins, Micah Peace, Sara Luterman, Ben Barnhart, Jacob Bouma-Sims, Jessica Riley, Janet Shouse, Ravita Maharaj, Cordelia R. Rosenberg, Karyn Harvey, Juliana Huereña, Katy Schmid, and Jennifer S. Alexander. “Improving Research and Practice: Priorities for Young Adults with Intellectual/Developmental Disabilities and Mental Health Needs.” *Journal of Mental Health Research in Intellectual Disabilities,* 2019, online ahead of print.

Kramer, Jessica, Yishai Barth, Katie Curtis, Kit Livingston, Madeline O'Neil, Zach Smith, Samantha Vallier, and Ashley Wolfe. “Involving Youth with Disabilities in the Development and Evaluation of a New Advocacy Training: Project TEAM.” *Disability and Rehabilitation,* vol. 35, no. 7, 2013, pp. 614–622.

Kratz, A.L., C.Z. Kalpakjian, and R.A. Hanks. “Are Intensive Data Collection Methods in Pain Research Feasible in Those with Physical Disability? A Study in Persons with Chronic Pain and Spinal Cord Injury.” *Quality of Life,* vol. 26, no. 3, 2017, pp. 587–600.

Krol, M., H. Sixma, J. Meerdink, H. Wiersma, and J. Rademakers. “Exploring Young Patients’ Perspectives on Rehabilitation Care: Methods and Challenges of Organizing Focus Groups for Children and Adolescents.” *Child: Care, Health and Development,* vol. 40, no. 4, 2014, pp. 507–514.

Krops, Leonie A., Linda Wolthuizen, Pieter U. Dijkstra, Eva A. Jaarsma, Jan H.B. Geertzen, and Rienk Dekker. “Reliability of Translation of the RAND 36-Item Health Survey in a Post-Rehabilitation Population.” *International Journal of Rehabilitation Research,* vol. 41, no. 2, 2018, pp. 128–137.

Krueger, Alice B., Patrice Colletti, Hillary R. Bogner, Frances K. Barg, and Margaret G. Stineman. “Conducting Focus Groups in Second Life® on Health-Related Topics.” *Journal of Alternative Medicine Research,* vol. 9, no. 2, 2017, pp. 135–139.

Kushalnagar, Poorna, Raychelle Harris, Raylene Paludneviciene, and TraciAnn Hoglind. “Health Information National Trends Survey in American Sign Language (HINTS-ASL): Protocol for the Cultural Adaptation and Linguistic Validation of a National Survey.” *JMIR Research Protocols,* vol. 6, no. 9, 2017, 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.

Kyrölä, Kati, Arja H. Häkkinen, Jari Ylinen, and Jussi P. Repo. "Further Validation of the Scoliosis Research Society (SRS-30) Questionnaire Among Adult Patients with Degenerative Spinal Disorder." *Disability and Rehabilitation,* 2019, online ahead of print.

Labreche, Tammy, Krithika Nandakumar, Mohammed Althomali, and Susan J. Leat. "Development and Validation of Visual Impairment as a Risk for Falls Questionnaire." *Age and Ageing,* vol. 47, no. 3, 2018, pp. 444–450.

Lauer, Eric A., and Andrew J. Houtenville. "Estimates of Prevalence, Demographic Characteristics and Social Factors Among People with Disabilities in the USA: A Cross-Survey Comparison." *BMJ Open,* vol. 8, 2018, online only.

Lauer, Eric A., Megan Henly, and Rachel Coleman. "Comparing Estimates of Disability Prevalence Using Federal and International Disability Measures in National Surveillance." *Disability and Health Journal,* vol. 12, no. 2, 2019, pp. 195–202.

Leahy, Edmund, Megan Davidson, Deenika Benjamin, and Henry Wajswelner. "Patient-Reported Outcome (PRO) Questionnaires for People with Pain in Any Spine Region. A Systematic Review." *Manual Therapy,* vol. 22, 2016, pp. 22–30.

Ledger, Susan, Yu S. Bin, Monica Nour, Peter Cistulli, Adrian Bauman, Margaret Allman-Farinelli, Sharon L. Naismith, Emmanuel Stamatakis, Corinne Caillaud, Philip De Chazal, et al. "Internal Consistency and Convergent and Divergent Validity of the Liverpool Jetlag Questionnaire." *Chronobiology International: The Journal of Biological and Medical Rhythm Research,* vol. 37, no. 2, 2020, pp. 218–226.

Lee, Sharon S.S., Xiaohui Xin, Wan P. Lee, Eugene J. Sim, Benedict Tan, Michael P.G. Bien, Alexander S.T. Lau, and Julian Thumboo. "The Feasibility of Using SMS as a Health Survey Tool: An Exploratory Study in Patients with Rheumatoid Arthritis." *International Journal of Medical Informatics,* vol. 82, no. 5, 2013, pp. 427–434.

Lequerica, Anthony H., Nancy D. Chiaravalloti, Angelle M. Sander, Monique R. Pappadis, Juan C. Arango-Lasprilla, Tessa Hart, James H. Baños, Carlos Marquez De La Plata,, Flora M. Hammond, and Tanya E. Sherman. "The Community Integration Questionnaire: Factor Structure Across Racial/Ethnic Groups in Persons with Traumatic Brain Injury." *The Journal of Head Trauma Rehabilitation,* vol. 28, no. 6, 2013, pp. E14–E22.

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.

Liew, Hui-Peng, and Sheena Gardner. "Exploring the Use of Paradata in Predicting Nonresponse in the Indonesian Family Life Survey." *Bulletin of Sociological Methodology,* vol. 126, no. 1, 2015, pp. 99–108.

Liljenquist, K., W. Coster, J. Kramer, and Z. Rossetti. "Feasibility of the Participatory Experience Survey and the Setting Affordances Survey for Use in Evaluation of Programmes Serving Youth with Intellectual and Developmental Disabilities." *Child: Care, Health and Development,* vol. 43, no. 4, 2017, pp. 511–517.

Liljenquist, Kendra, Jessica Kramer, Zachary Rossetti, and Wendy Coster. "Content Development, Accessibility and Feasibility of a Self-Report Tool for Use in Programmes Serving Youth with Cognitive Disabilities: The Participatory Experience Survey." *Australian Occupational Therapy Journal,* vol. 66, no. 4, 2019, pp. 490–499.

Lima-Castro, Sandra, Vanessa Blanco, Patricia Otero, Lara López, and Fernando L. Vázquez. "Health-Related Quality of Life Among Persons with Physical Disabilities: A Systematic Review and Meta-Analysis." *Revista Iberoamericana De Psicología y Salud,* vol. 11, no. 2, 2020, pp. 82–102.

Lindgren, Noora, Juha O. Rinne, Teemu Palviainen, Jaakko Kaprio, and Eero Vuoksimaa. "Prevalence and Correlates of Dementia and Mild Cognitive Impairment Classified with Different Versions of the Modified Telephone Interview for Cognitive Status (TICS–m)." *International Journal of Geriatric Psychiatry,* vol. 34, no. 12, 2019, pp. 1883–1891.

Lipinski, Silke, Elisabeth S. Blanke, Ulrike Suenkel, and Isabel Dziobek. "Outpatient Psychotherapy for Adults with High-Functioning Autism Spectrum Condition: Utilization, Treatment Satisfaction, and Preferred Modifications." *Journal of Autism and Developmental Disorders,* vol. 49, 2019, pp. 1154–1168.

Littlejohn, Jenna, Daniel Blackburn, and Annalena Venneri. "Understanding the Links Between Hearing Impairment and Dementia: Development and Validation of the Social and Emotional Impact of Hearing Impairment (SEI-HI) Questionnaire." *Neurological Sciences,* vol. 41, no. 12, 2020, pp. 3711–3717.

Liu, Mingnan, Sunghee Lee, Mengyao Hu, and Colleen McClain. "Increasing Cross-National Comparability of Disability Measures with Anchoring Vignettes." Presented at the American Association for Public Opinion Research conference, Anaheim, CA, May 2014.

Livingston, Nicholas A., Tannis Hargrove, Lillie Greiman, Andrew Myers, Catherine Ipsen, and Craig Ravesloot. "An Investigation into the Temporal Scaling of Community Participation Measurement." *Rehabilitation Psychology,* vol. 60, no. 4, 2015, pp. 367–375.

Lloyd, Owen, Tamara Ownsworth, Jennifer Fleming, and Melanie Zimmer-Gembeck. "Development and Preliminary Validation of the Paediatric Awareness Questionnaire for Children and Adolescents with Traumatic Brain Injury." *Child Neuropsychology,* vol. 24, no. 5, 2018, pp. 702–722.

Loeb, Mitchell, Daniel Mont, Claudia Cappa, Elena De Palma, Jennifer Madans, and Roberta Crialesi. "The Development and Testing of a Module on Child Functioning for Identifying Children with Disabilities on Surveys. I: Background." *Disability and Health Journal,* vol. 11, no. 4, 2018, pp. 495–501.

Lutomski, Jennifer E., Maria A.E. Baars, Janneke A. van Kempen, Bianca M. Buurman, Wendy P.J. den Elzen, Aaltje P.D. Jansen, Gertrudis I.J.M. Kempen, Paul F.M. Krabbe, Bas Steunenberg, Ewout W. Steyerberg, Marcel G.M. Olde-Rikkert, and René J.F. Melis. "Validation of a Frailty Index from the Older Persons and Informal Caregivers Survey Minimum Data Set." *Journal of the American Geriatrics Society,* vol. 61, no. 9, 2013, pp. 1625–1627.

Lysaght, Rosemary, Rachelle Kranenburg, Carolyn Armstrong, and Terry Krupa. "Participant Recruitment for Studies on Disability and Work: Challenges and Solutions." *Journal of Occupational Rehabilitation,* vol. 26, no. 2, 2016, pp. 125–140.

Macháčová, Kateřina, Hana Vaňková, Iva Holmerová, Inna Čábelková, and Ladislav Volicer. "Ratings of Activities of Daily Living in Nursing Home Residents: Comparison of Self- and Proxy Ratings with Actual Performance and the Impact of Cognitive Status." *European Journal of Ageing,* vol. 15, no. 4, 2018, pp. 349–358.

Mack, Jennifer W., Molly McFatrich, Janice S. Withycombe, Scott H. Maurer, Shana S. Jacobs, Li Lin, Nicole R. Lucas, Justin N. Baker, Courtney M. Mann, Lillian Sung, et al. "Agreement Between Child Self-Report and Caregiver-Proxy Report for Symptoms and Functioning of Children Undergoing Cancer Treatment." *JAMA Pediatrics,* vol. 174, no. 11, 2020, online only.

Madden, R. H., S. Lukersmith, Q. Zhou, M. Glasgow, and S. Johnston. "Disability-Related Questions for Administrative Datasets." *International Journal of Environmental Research and Public Health,* vol. 17, no. 15, 2020, pp. 1–17.

Maddox, Brenna B., Luc Lecavalier, Judith S. Miller, Jill Pritchett, Jill Hollway, Susan W. White, Scott Gillespie, Andrea N. Evans, Robert T. Schultz, John D. Herrington, et al. "Reliability and Validity of the Pediatric Anxiety Rating Scale Modified for Autism Spectrum Disorder." *Autism: The International Journal of Research & Practice,* vol. 24, no. 7, 2020, pp. 1773–1782.

Makic, Mary B., Danielle Gilbert, Catherine Jankowski, Blaine Reeder, Nasser Al-Salmi, Whitney Starr, and Paul F. Cook. "Sensor and Survey Measures Associated with Daily Fatigue in HIV: Findings from a Mixed-Method Study." *JANAC: Journal of the Association of Nurses in AIDS Care,* vol. 31, no. 1, 2020, pp. 12–24.

Manchaiah, Vinaya, Sarah Granberg, Vibhu Grover, Gabrielle H. Saunders, and Deborah Ann Hall. "Content Validity and Readability of Patient-Reported Questionnaire Instruments of Hearing Disability." *International Journal of Audiology,* vol. 59, no. 9, 2019, pp. 565–575.

Margot-Cattin, Isabel, Nicolas Kuhne, Anders Kottorp, Malcolm Cutchin, Annika Öhman, and Louise Nygård. "Development of a Questionnaire to Evaluate Out-of-Home Participation for People with Dementia." *The American Journal of Occupational Therapy,* vol. 73, 2019, online only.

Marino, Molly E., Mark Meterko, Elizabeth E. Marfeo, Christine M. McDonough, Alan M. Jette, Pengsheng Ni, Kara Bogusz, Elizabeth K. Rasch, Diane E. Brandt, and Leighton Chan. "Work-Related Measures of Physical and Behavioral Health Function: Test-Retest Reliability." *Disability and Health Journal,* vol. 8, no. 4, 2015, pp. 652–657.

Markesich, Jason A., Anne B. Ciemnecki, and Karen A. CyBulski. "Nothing About Them Without Them: Strategies for Including Hard-to-Reach People with Disabilities in Survey Research." Paper presented at the H2R International Conference on Methods for Surveying and Enumerating Hard-to-Reach Populations, New Orleans, LA, November 2012.

Markesich, Jason, Ryan Callahan, Jesse Chandler, and Amy Johnson. "Using Behavioral Science to Improve Survey Participation: An Experiment with the National Beneficiary Survey." Presented at the 2017 Annual Disability Statistics Compendium Event, Washington, DC, February 2018.

Markowitz, Leslie A., Charina Reyes, Rebecca A. Embacher, Leslie L. Speer, Nancy Roizen, and Thomas W. Frazier. "Development and Psychometric Evaluation of a Psychosocial Quality-of-Life Questionnaire for Individuals with Autism and Related Developmental Disorders." *Autism,* vol. 20, no. 7, 2016, pp. 832–844.

Marmeleira, José, Luís Laranjo, Olga Marques, and Nuno Batalha. "Criterion-Related Validity of the Short Form of the International Physical Activity Questionnaire in Adults Who Are Blind." *Journal of Visual Impairment & Blindness,* vol. 107, no. 5, 2013, pp. 375–381.

Mason, Lisa H., Anne L. Shandera-Ochsner, Kimberly D. Williamson, Jordan P. Harp, Maryanne Edmundson, David T.R. Berry, and Walter M. High Jr. "Accuracy of MMPI-2-RF Validity Scales for Identifying Feigned PTSD Symptoms, Random Responding, and Genuine PTSD." *Journal of Personality Assessment,* vol. 95, no. 6, 2013, pp. 585–593.

Massey, Meredith. "The Development and Testing of a Module on Child Functioning for Identifying Children with Disabilities on Surveys. II: Question Development and Pretesting." *Disability and Health Journal,* vol. 11, no. 4, 2018, pp. 502–509.

Mathews, Megan, Denis Agniel, Marc N. Elliott, Steven C. Martino, Paul Guerino, Nate Orr, Judy H. Ng, and Megan K. Beckett. "The Development of a Patient-Reported Functional Limitations Index." *American Journal of Managed Care,* vol. 26, no. 7, 2020, pp. e225–e231.

Matulewicz, Holly, Karen Donelan, and Forest Crigler. "Challenges and Opportunities in Engaging Low-Income Populations with Disabilities in Web Surveys." Presented at the American Association for Public Opinion Research conference, New Orleans, LA, May 2017.

McDonald, Katherine E., and Erin Stack. "You Say You Want a Revolution: An Empirical Study of Community-Based Participatory Research with People with Developmental Disabilities." *Disability and Health Journal,* vol. 9, no. 2, 2016, pp. 201–207.

McKenzie, Karen, Dale Metcalfe, and George Murray. "A Review of Measures Used in the Screening, Assessment and Diagnosis of Dementia in People with an Intellectual Disability." *Journal of Applied Research in Intellectual Disabilities,* vol. 31, no. 5, 2018, pp. 725–742.

McKenzie, Karen, George Murray, Aja Murray, Rachel Martin, Yasmin Tanfield, Lauren Delahunty, Linda Hutton, Kara R. Murray, and Anne O'Hare. "Screening for Intellectual Disability with the Child and Adolescent Intellectual Screening Questionnaire: A Modified Delphi Approach." *Developmental Medicine & Child Neurology,* vol. 61, no. 8, 2019, pp. 979–983.

McKenzie, Karen, George Murray, Linda Hutton, Aja Murray, Lauren Delahunty, Anne O'Hare, and Kara Murray. "Child and Adolescent Intellectual Disability Screening Questionnaire to Identify Children with Intellectual Disability." *Developmental Medicine & Child Neurology,* vol. 61, no. 4, 2019, pp. 444–450.

McKeon, Ashlee, Michael McCue, Elizabeth Skidmore, Michelle Schein, and Jamie Kulzer. "Ecological Momentary Assessment for Rehabilitation of Chronic Illness and Disability." *Disability and Rehabilitation,* vol. 40, no. 8, 2018, pp. 974–987.

Menezes, Diogo, Luís Laranjo, and José Marmeleira. "Criterion-Related Validity of the Short Form of the International Physical Activity Questionnaire in Adults Who Are Deaf." *Disability and Health Journal,* vol. 10, no. 1, 2017, pp. 33–38.

Mensch, S.M., M.A. Echteld, R. Lemmens, A. Oppewal, H.M. Evenhuis, and E.A.A. Rameckers. "The Relationship Between Motor Abilities and Quality of Life in Children with Severe Multiple Disabilities." *Journal of Intellectual Disability Research,* vol. 63, no. 2, 2019, pp. 100–112.

Mevissen, Liesbeth, Robert Didden, Ad de Jongh, and Hubert Korzilius. "Assessing Posttraumatic Stress Disorder in Adults with Mild Intellectual Disabilities or Borderline Intellectual Functioning." *Journal of Mental Health Research in Intellectual Disabilities,* vol. 13, no. 2, 2020, pp. 110–126.

Michel, Jeremy J., Stephanie Mayne, Robert W. Grundmeier, James P. Guevara, Nathan J. Blum, Thomas J. Power, Emily Coffin, Jeffrey M. Miller, and Alexander G. Fiks. "Sharing of ADHD Information Between Parents and Teachers Using an EHR-Linked Application." *Applied Clinical Informatics,* vol. 9, no. 4, 2018, pp. 892–904.

Michel, Pierre, Karine Baumstarck, Christophe Lancon, Badih Ghattas, Anderson Loundou, Pascal Auquier, and Laurent Boyer. "Modernizing Quality of Life Assessment: Development of a Multidimensional Computerized Adaptive Questionnaire for Patients with Schizophrenia." *Quality of Life Research,* vol. 27, no. 4, 2018, pp. 1041–1054.

Mileviciute, I., and S.L. Hartley. "Self-Reported Versus Informant-Reported Depressive Symptoms in Adults with Mild Intellectual Disability." *Journal of Intellectual Disability Research,* vol. 59, no. 2, 2015, pp. 158–169.

Milne, Rebecca, Stefanie J. Sharman, Martine B. Powell, and Sarah Mead. "Assessing the Effectiveness of the Cognitive Interview for Children with Severe Intellectual Disabilities." *International Journal of Disability, Development and Education,* vol. 60, no. 1, 2013, pp. 18–29.

Milner, Paul, and Patsie Frawley. "From 'on' to 'with' to 'by:' People with a Learning Disability Creating a Space for the Third Wave of Inclusive Research." *Qualitative Research,* vol. 19, no. 4, 2019, pp. 382–398.

Minen, Mia T., Kaitlyn Morio, Kathryn B. Schaubhut, Scott W. Powers, Richard B. Lipton, and Elizabeth Seng. "Focus Group Findings on the Migraine Patient Experience During Research Studies and Ideas for Future Investigations." *Cephalalgia,* vol. 40, no. 7, 2020, pp. 712–734.

Miranda-Castillo, Claudia, Bob Woods, and Martin Orrell. "The Needs of People with Dementia Living at Home from User, Caregiver and Professional Perspectives: A Cross-Sectional Survey." *BMC Health Services Research,* vol. 13, no. 43, 2013, online only.

Mirmosayyeb, Omid, Vahid Shaygannejad, and Mahsa Ghajarzadeh. "Comparison of Psychological Difficulties in Patients with Migraine and Epilepsy Using PARADISE-24 Questionnaire." *Journal of Multidisciplinary Healthcare,* vol. 13, 2020, pp. 609–613.

Mitchell, Fraser. "Reflections on the Process of Conducting Secondary Analysis of Qualitative Data Concerning Informed Choice for Young People with a Disability in Transition." *Forum: Qualitative Social Research,* vol. 16, no. 3, 2015, pp. 1–12.

Mood, Laura, Dena Hassouneh, and Elizabeth McNeff. "A Conceptual Model to Promote the Retention of Women with Physical Disabilities in Research." *Public Health Nursing,* vol. 32, no. 4, 2015, pp. 368–377.

Moreland, Christopher J., Darin Latimore, Ananda Sen, Nora Arato, and Philip Zazove. "Deafness Among Physicians and Trainees: A National Survey." *Academic Medicine,* vol. 88, no. 2, 2013, pp. 224–232.

Morgan, Kerri A., Meghan Gottlieb, Holly H. Hollingsworth, and David B. Gray. "Work Environments of People with Mobility Impairments and Limitations: Mobility Device User Work Survey (MWS)." *Work,* vol. 48, no. 3, 2014, pp. 339–348.

Morgan, Michelle F., Karen B. Moni, and Monica Cuskelly. "The Development of Research Skills in Young Adults with Intellectual Disability in Participatory Research." *International Journal of Disability, Development and Education,* vol. 62, no. 4, 2015, pp. 438–457.

Morin, D., P. Valois, A.G. Crocker, and C. Robitaille. "Development and Psychometric Properties of the Attitudes Toward Intellectual Disability Questionnaire – Short Form." *Journal of Intellectual Disability Research,* vol. 63, no. 6, 2019, pp. 539–547.

Moss, Sarah J., and Stanislaw H. Czyz. "Level of Agreement Between Physical Activity Levels Measured by ActiHeart and the International Physical Activity Questionnaire in Persons with Intellectual Disability." *Disability and Rehabilitation,* vol. 40, no. 3, 2018, pp. 360–366.

Mu, Dong-Liang, Pan-Pan Ding, Shu-Zhe Zhou, Mei-Jing Liu, Xin-Yu Sun, Xue-Ying Li, and Dong-Xin Wang. "Cross-Cultural Adaptation and Validation of the 3D-CAM Chinese Version in Surgical ICU Patients." *BMC Psychiatry,* vol. 20, no. 1, 2020, pp. 1–7.

Murphy, Dominic, Mark Shevlin, Emily Pearson, Neil Greenberg, Simon Wessely, Walter Busuttil, and Thanos Karatzias. "A Validation Study of the International Trauma Questionnaire to Assess Post-Traumatic Stress Disorder in Treatment-Seeking Veterans." *The British Journal of Psychiatry,* vol. 216, no. 3, 2020, pp. 132–137.

Nicholas, Marjorie, Lindsay Jennelle, Lisa T. Connor, Charles Haynes, and Lauryn Zipse. "Do Caregiver Proxy Reports and Congruence of Client-proxy Activity Participation Goals Relate to Quality of Life in People with Aphasia?" *International Journal of Language & Communication Disorders,* vol. 55, no. 3, 2020, pp. 373–386.

Nicolaidis, Christina, Dora M. Raymaker, Katherine E. McDonald, Emily M. Lund, Sandra Leotti, Steven K. Kapp, Marsha Katz, Leanne M. Beers, Clarissa Kripke, Joelle Maslak, et al. "Creating Accessible Survey Instruments for Use with Autistic Adults and People with Intellectual Disability: Lessons Learned and Recommendations." *Autism in Adulthood: Challenges and Management,* vol. 2, no.

Nicolaidis, Christina, Dora Raymaker, Katherine McDonald, Sebastian Dern, W. Cody Boisclair, Elesia Ashkenazy, and Amanda Baggs. "Comparison of Healthcare Experiences in Autistic and Non-Autistic Adults: A Cross-Sectional Online Survey Facilitated by an Academic-Community Partnership." *Journal of General Internal Medicine,* vol. 28, no. 6, 2013, pp. 761–769.

Nicolaidis, Christina, Dora Raymaker, Marsha Katz, Mary Oschwald, Rebecca Goe, Sandra Leotti, Leah Grantham, Eddie Plourde, Janice Salomon, Rosemary B. Hughes, and Laurie E. Powers. "Community-Based Participatory Research to Adapt Health Measures for Use by People with Developmental Disabilities." *Progress in Community Health Partnerships: Research, Education, and Action,* vol. 9, no. 2, 2015, pp. 157–170.

Nielsen, Anne M., Werner Vach, Peter Kent, Lise Hestbaek, and Alice Kongsted. "Using Existing Questionnaires in Latent Class Analysis: Should We Use Summary Scores or Single Items as Input? A Methodological Study Using a Cohort of Patients with Low Back Pain." *Clinical Epidemiology,* vol. 8, 2016, pp. 73–89.

Niemensivu, Riina, Risto P. Roine, Harri Sintonen, and Erna Kentala. "Health-Related Quality of Life in Hearing-Impaired Adolescents and Children." *Acta Oto-Laryngologica,* vol. 138, no. 7, 2018, pp. 652–658.

Nilsen, Marci L., Lingyun Lyu, Michael A. Belsky, Leila J. Mady, Dan P. Zandberg, David A. Clump, Heath D. Skinner, Shyamal D. Peddada, Susan George, and Jonas T. Johnson. "Impact of Neck Disability on Health-Related Quality of Life Among Head and Neck Cancer Survivors." *Otolaryngology–Head and Neck Surgery,* vol. 162, no. 1, 2020, pp. 64–72.

Nind, Melanie, and Hilra Vinha. "Creative Interactions with Data: Using Visual and Metaphorical Devices in Repeated Focus Groups." *Qualitative Research,* vol. 16, no. 1, 2016, pp. 9–26.

Nolan, Laura. "An Exploration of Proxy- and Self-Reported Adolescent Health in Low-Resource Settings." *Survey Research Methods,* vol. 10, no. 2, 2016, pp. 65–83.

Northway, Ruth, Joyce Howarth, and Lynne Evans. "Participatory Research, People with Intellectual Disabilities and Ethical Approval: Making Reasonable Adjustments to Enable Participation." *Journal of Clinical Nursing,* vol. 24, no. 3–4, 2015, pp. 573–581.

O'Brien, Dai. "Visual Research with Young d/Deaf People - An Investigation of the Transitional Experiences of d/Deaf Young People from Mainstream Schools Using Auto-Driven Photo-Elicitation Interviews." *Graduate Journal of Social Science,* vol. 10, no. 2, 2013, pp. 152–175.

O'Brien, Kelly K., Ahmed M. Bayoumi, Paul Stratford, and Patricia Solomon. "Which Dimensions of Disability Does the HIV Disability Questionnaire (HDQ) Measure? A Factor Analysis." *Disability and Rehabilitation,* vol. 37, no. 13, 2015, pp. 1193–1201.

O'Brien, Kelly K., Tarik Bereket, Marilyn Swinton, and Patricia Solomon. "Using Qualitative Methods to Assess the Measurement Property of a New HIV Disability Questionnaire." *International Journal of Qualitative Methods,* vol. 12, 2013, online only.

O'Brien, Patricia, Roy McConkey, and Edurne García-Iriarte. "Co-Researching with People Who Have Intellectual Disabilities: Insights from a National Survey." *Journal of Applied Research in Intellectual Disabilities,* vol. 27, no. 1, 2014, pp. 65–75.

O'Dwyer, John L., Amy M. Russell, Louise D. Bryant, Rebecca E.A. Walwyn, Alexandra M. Wright-Hughes, Elizabeth H. Graham, Judy M. Wright, Shaista Meer, Jacqueline Birtwistle, Amanda J. Farrin, Allan O. House, and Claire T. Hulme. "Developing and Feasibility Testing of Data Collection Methods for an Economic Evaluation of a Supported Selfmanagement Programme for Adults with a Learning Disability and Type 2 Diabetes." *BMC Pilot and Feasibility Studies,* vol. 4, no. 80, 2018, online only.

O'Keeffe, Lynsey, Suzanne Guerin, John McEvoy, Karen Lockhart, and Philip Dodd. "The Process of Developing Self-Report Measures in Intellectual Disability: A Case Study of a Complicated Grief Scale." *British Journal of Learning Disabilities,* vol. 47, no. 2, 2019, pp. 134–144.

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.

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.

Oschwald, Mary, Sandy Leotti, Dora Raymaker, Marsha Katz, Rebecca Goe, Mark Harviston, Annie Wallington, Lisa Howard, Leanne Beers, Christina Nicolaidis, Susan Robinson-Whelen, Rosemary B. Hughes, Emily Lund, and Laurie E. Powers. "Development of an Audio-Computer Assisted Self-Interview to Investigate Violence and Health in the Lives of Adults with Developmental Disabilities." *Disability and Health Journal,* vol. 7, no. 3, 2014, pp. 292–301.

Ottmann, Goetz, and Jenny Crosbie. "Mixed Method Approaches in Open-Ended, Qualitative, Exploratory Research Involving People with Intellectual Disabilities: A Comparative Methods Study." *Journal of Intellectual Disabilities,* vol. 17, no. 3, 2013, pp. 182–197.

Overton, Eve, Paul S. Appelbaum, Stephanie R. Fisher, Daniel Dohan, Laura W. Roberts, and Laura B. Dunn. "Alternative Decision-Makers' Perspectives on Assent and Dissent for Dementia Research." *The American Journal of Geriatric Psychiatry,* vol. 21, no. 4, 2013, pp. 346–354.

Owens, J., K. Jones, and Z. Marshman. "The Oral Health of People with Learning Disabilities - A User-Friendly Questionnaire Survey." *Community Dental Health,* vol. 34, no. 1, 2017, pp. 4–7.

Packer, Jaclyn, and William Reuschel. "VoIP Accessibility: A Usability Study of Voice Over Internet Protocol (VoIP) Systems and a Survey of VoIP Users with Vision Loss." *Journal of Visual Impairment & Blindness,* vol. 112, no. 1, 2018, pp. 47–60.

Paladin, M., T. Kogovšek, and S. Pavlin. "How Do the Particular Characteristics of Less-Educated Employees with Disabilities Impact Survey Implementation?" *Work,* vol. 65, no. 4, 2020, pp. 707–719.

Pardo-Guijarro, María J., Bencie Woll, Pablo Moya-Martínez, María Martínez-Andrés, Eugenio E. Cortés-Ramírez, and Vicente Martínez-Vizcaíno. "Validity and Reliability of the Spanish Sign Language Version of the KIDSCREEN-27 Health-Related Quality of Life Questionnaire for Use in Deaf Children and Adolescents." *Gaceta Sanitaria,* vol. 27, no. 4, 2013, pp. 318–324.

Paterson, Helen, and Christine Carpenter. "Using Different Methods to Communicate: How Adults with Severe Acquired Communication Difficulties Make Decisions About the Communication Methods They Use and How They Experience Them." *Disability and Rehabilitation,* vol. 37, no. 17, 2015, pp. 1522–1530.

Pedersen, H., S. Söderström, and P.S. Kermit. "Assistive Activity Technology as Symbolic Expressions of the Self." *Technology and Disability,* vol. 31, no. 3, 2019, pp. 129–140.

Pérez-Cruzado, D., and A.I. Cuesta-Vargas. "Energy Expenditure Measured with Accelerometers and Self-Report Questionnaire in People with Intellectual Disabilities." *Journal of Intellectual Disability Research,* vol. 62, no. 8, 2018, pp. 701–708.

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.

Perry, Adrienne, Meisha Charles, Busi Ncube, and Jonathan Weiss. "The GO4KIDDS School Satisfaction Scale." *Journal of Applied Research in Intellectual Disabilities,* vol. 32, no. 2, 2019, pp. 471–474.

Phillips, Kimberly, Andrew Houtenville, and Vidya Sundar. "Toward Better Disability Items on National Surveys." Presented at the American Statistical Association Joint Statistical Meetings, Chicago, IL, August 2016.

Pink, Joshua, Stavros Petrou, Esther Williamson, Mark Williams, and Sarah E. Lamb. "Properties of Patient-Reported Outcome Measures in Individuals Following Acute Whiplash Injury." *BMC Health and Quality of Life Outcomes,* vol. 12, no. 38, 2014, online only.

Postma, S.A.E., K. van Boven, H. Ten Napel, D.L. Gerritsen, W.J.J. Assendelft, H. Schers, and T.C. olde Hartman. "The Development of an ICF-Based Questionnaire for Patients with Chronic Conditions in Primary Care." *Journal of Clinical Epidemiology,* vol. 103, 2018, pp. 92–100.

Povee, Kate, Brian J. Bishop, and Lynne D. Roberts. "The Use of Photovoice with People with Intellectual Disabilities: Reflections, Challenges and Opportunities." *Disability & Society,* vol. 29, no. 6, 2014, pp. 893–907.

Printza, A., M. Boziki, C. Bakirtzis, I. Nikolaidis, M. Kalaitzi, S. Triaridis, and N. Grigoriadis. "The Modified DYMUS Questionnaire Is a Reliable, Valid and Easy-to-Use Tool in the Assessment of Dysphagia in Multiple Sclerosis." *European Journal of Neurology,* vol. 27, no. 7, 2020, pp. 1231–1237.

Prior, Sarah, Andrea Miller, Steven Campbell, Karen Linegar, and Gregory Peterson. "The Challenges of Including Patients with Aphasia in Qualitative Research for Health Service Redesign: Qualitative Interview Study." *Journal of Participatory Medicine,* vol. 12, no. 1, 2020, article no. e12336.

Propp, Roni, Laura McAdam, Aileen M. Davis, Nancy M. Salbach, Shannon Weir, Clarissa Encisa, and Unni G. Narayanan. "Development and Content Validation of the Muscular Dystrophy Child Health Index of Life with Disabilities Questionnaire for Children with Duchenne Muscular Dystrophy." *Developmental Medicine & Child Neurology,* vol. 61, no. 1, 2019, pp. 75–81.

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.

Purcal, Christiane, Karen R. Fisher, Sally Robinson, Ariella Meltzer, and Ngila Bevan. "Co-Production in Peer Support Group Research with Disabled People." *Area,* vol. 51, no. 3, 2019, pp. 405–414.

Puyalto, Carol, Maria Pallisera, Judit Fullana, and Montserrat Vilà. "Doing Research Together: A Study on the Views of Advisors with Intellectual Disabilities and Non-Disabled Researchers Collaborating in Research." *Journal of Applied Research in Intellectual Disabilities,* vol. 29, no. 2, 2016, pp. 146–159.

Raczka, Roman, Kate Theodore, and Janice Williams. "An Initial Validation of a New Quality of Life Measure for Adults with Intellectual Disability: The Mini-MANS-LD." *Journal of Intellectual Disabilities,* vol. 24, no. 2, 2020, pp. 177–193.

Raggi, Alberto, Venusia Covelli, Erika Guastafierro, Matilde Leonardi, Chiara Scaratti, Licia Grazzi, Marco Bartolini, Giovanna Viticchi, Sabina Cevoli, Giulia Pierangeli, Gioacchino Tedeschi, Antonio Russo, Piero Barbanti, Cinzia Aurilia, Carlo Lovati, Luca Giani, Fabio Frediani, Paola Di Fiore, Francesco Bono, Laura Rapisarda, and Domenico D'Amico. "Validation of a Self-Reported Instrument to Assess Work-Related Difficulties in Patients with Migraine: The HEADWORK Questionnaire." *The Journal of Headache and Pain,* vol. 19, no. 85, 2018, online only.

Raghunath, Nisha, Jessamyn Dahmen, Katelyn Brown, Diane Cook, and Maureen Schmitter-Edgecombe. "Creating a Digital Memory Notebook Application for Individuals with Mild Cognitive Impairment to Support Everyday Functioning." *Disability and Rehabilitation: Assistive Technology,* 2019, online ahead of print.

Rakusa, Martin, Joze Jensterle, and Janez Mlakar. "Clock Drawing Test: A Simple Scoring System for the Accurate Screening of Cognitive Impairment in Patients with Mild Cognitive Impairment and Dementia." *Dementia and Geriatric Cognitive Disorders,* vol. 45, no. 5, 2018, pp. 326–334.

Raley, Sheida K., Karrie A. Shogren, Graham G. Rifenbark, Mark H. Anderson, and Leslie A. Shaw. "Comparing the Impact of Online and Paper-and-Pencil Administration of the Self-Determination Inventory: Student Report." *Journal of Special Education Technology,* vol. 35, no. 3, 2020, pp. 133–144.

Ramke, Jacqueline, Anna Palagyi, Hannah Kuper, and Clare E. Gilbert. "Assessment of Response Bias Is Neglected in Cross-Sectional Blindness Prevalence Surveys: A Review of Recent Surveys in Low- and Middle-Income Countries." *Ophthalmic Epidemiology,* vol. 25, no. 5, 2018, pp. 379–385.

Rand, Stacey, James Caiels, Grace Collins, and Julien Forder. "Developing a Proxy Version of the Adult Social Care Outcome Toolkit (ASCOT)." *BMC Health and Quality of Life Outcomes,* vol. 15, no. 108, 2017, online only.

Raven-Takken, Evelijn, Nicole Ter Wal, and Lizet Van Ewijk. "What Minimum Level of Language Comprehension Is Required for Reliable Administration of the SAQOL-39NLg?" *Aphasiology,* vol. 34, no. 6, 2020, pp. 674–687.

Rice, L.J., E. Emerson, K.M. Gray, P. Howlin, B.J. Tonge, G.L. Warner, and S.L. Einfeld. "Concurrence of the Strengths and Difficulties Questionnaire and Developmental Behaviour Checklist Among Children with an Intellectual Disability." *Journal of Intellectual Disability Research,* vol. 62, no. 2, 2018, pp. 150–155.

Riches, Tanya N., and Patricia M. O'Brien. "Can We Publish Inclusive Research Inclusively? Researchers with Intellectual Disabilities Interview Authors of Inclusive Studies." *British Journal of Learning Disabilities,* vol. 48, no. 4, 2020, pp. 272–280.

Rietdijk, Rachael, Emma Power, Melissa Brunner, and Leanne Togher. "Reliability of Videoconferencing Administration of a Communication Questionnaire to People with Traumatic Brain Injury and Their Close Others." *The Journal of Head Trauma Rehabilitation,* vol. 32, no. 6, 2017, pp. E38–E44.

Rix, Jonathan, Helena G. Carrizosa, Jane Seale, Kieron Sheehy, and Simon Hayhoe. "The While of Participation: A Systematic Review of Participatory Research Involving People with Sensory Impairments and/or Intellectual Impairments." *Disability & Society,* 2019, online ahead of print.

Robertson, Jane M. "Using Carer Biographical Narratives to Explore Factors Involved in Proxy Reporting of Quality of Life in People with Dementia." *Aging & Mental Health,* vol. 21, no. 4, 2017, pp. 416–425.

Robinson-Cimpian, Joseph. "Inaccurate Estimation of Disparities Due to Mischievous Responders: Several Suggestions to Assess Conclusions." *Educational Researcher,* vol. 43, no. 4, 2014, pp. 171–185.

Rose, Tanya, Jessica Waterson, and Emma Caird. "The Communication Research Registry: Facilitating Access to Research Experiences for People with a Communication Disability." *Speech, Language and Hearing,* vol. 23, no. 4, 2020, pp. 208–220.

Roydhouse, Jessica K., Roee Gutman, Nancy L. Keating, Vince Mor, and Ira B. Wilson. "Propensity Scores for Proxy Reports of Care Experience and Quality: Are They Useful?" *Health Services & Outcomes Research Methodology,* vol. 20, no. 1, 2020, pp. 40–59.

Sabariego, Carla, Cornelia Oberhauser, Aleksandra Posarac, Jerome Bickenbach, Nenad Kostanjsek, Somnath Chatterji, Alana Officer, Michaela Coenen, Lay Chhan, and Alarcos Cieza. “Measuring Disability: Comparing the Impact of Two Data Collection Approaches on Disability Rates.” *International Journal of Environmental Research and Public Health,* vol. 12, no. 9, 2015, pp. 10329–10351.

Şahinoğlu, Ertan, Gülbin Ergin, and Bayram Ünver. “Psychometric Properties of Patient-Reported Outcome Questionnaires for Patients with Musculoskeletal Disorders of the Shoulder.” *Knee Surgery, Sports Traumatology, Arthroscopy,* vol. 27, no. 10, 2019, pp. 3188–3202.

Salzer, Mark S., Eugene Brusilovskiy, Janet Prvu-Bettger, and Petra Kottsieper. “Measuring Community Participation of Adults with Psychiatric Disabilities: Reliability of Two Modes of Data Collection.” *Rehabilitation Psychology,* vol. 59, no. 2, 2014, pp. 211–219.

Sander, Angelle M., Allison N. Clark, Laura M. van Veldhoven, Robin Hanks, Tessa Hart, Luis L. Novelo, Esther Ngan, and David B. Arciniegas. “Factor Analysis of the Everyday Memory Questionnaire in Persons with Traumatic Brain Injury.” *Clinical Neuropsychologist,* vol. 32, no. 3, 2018, pp. 495–509.

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.

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.

Schützwohl, Matthias, Elke Voß, Hans J. Salize, Maja Stiawa, Bernd Puschner, and Andrea Koch. “Self- and Proxy-Rated Needs in Adults with Mild to Moderate Intellectual Disabilities: Perspective Matters.” *Journal of Applied Research in Intellectual Disabilities,* vol. 31, no. 2, 2018, pp. 285–295.

Schwartz, Ariel E., and Brendan Durkin. “‘Team is Everything': Reflections on Trust, Logistics and Methodological Choices in Collaborative Interviewing” *British Journal of Learning Disabilities,* vol. 48, no. 2, 2020, pp. 115–123.

Schwartz, Ariel E., and Jessica M. Kramer. “Inclusive Approaches to Developing Content Valid Patient-Reported Outcome Measure Response Scales for Youth with Intellectual/Developmental Disabilities.” *British Journal of Learning Disabilities.* Published ahead of print, October 6, 2020.

Schwartz, Ariel E., Jessica M. Kramer, Ellen S. Cohn, and Katherine E. McDonald. "'That Felt Like Real Engagement': Fostering and Maintaining Inclusive Research Collaborations with Individuals with Intellectual Disability" *Qualitative Health Research,* vol. 30, no. 2, 2020, pp. 236–249.

Schwartz, Carolyn, Armon Ayandeh, Jonathan Rodgers, Paul Duberstein, Bianca Weinstock-Guttman, Ralph Benedict, Carolyn E. Schwartz, Jonathan D. Rodgers, and Ralph H. B. Benedict. "A New Perspective on Proxy Report: Investigating Implicit Processes of Understanding Through Patient-Proxy Congruence." *Quality of Life Research,* vol. 24, no. 11, 2015, pp. 2637–2649.

Scott, Daniel J., J. Devin B. Watson, Thomas A. Heafner, Michael S. Clemens, Brandon W. Propper, and Zachary M. Arthurs. "Validation of the Short Musculoskeletal Function Assessment in Patients with Battlefield-Related Extremity Vascular Injuries." *Journal of Vascular Surgery,* vol. 60, no. 6, 2014, pp. 1620–1626.

Scott, Haleigh M., and Susan M. Havercamp. "Comparison of Self- and Proxy Report of Mental Health Symptoms in People with Intellectual Disabilities." *Journal of Mental Health Research in Intellectual Disabilities,* vol. 11, no. 2, 2018, pp. 143–156.

Scott, Haleigh M., and Susan M. Havercamp. "Comparisons of Self and Proxy Report on Health-Related Factors in People with Intellectual Disability." *Journal of Applied Research in Intellectual Disabilities,* vol. 31, no. 5, 2018, pp. 927–936.

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.

Seelye, Adriana, Nora Mattek, Nicole Sharma, Thomas Riley, Johanna Austin, Katherine Wild, Hiroko H. Dodge, Emily Lore, and Jeffrey Kaye. "Weekly Observations of Online Survey Metadata Obtained Through Home Computer Use Allow for Detection of Changes in Everyday Cognition Before Transition to Mild Cognitive Impairment." *Alzheimer's & Dementia,* vol. 14, no. 2, 2018, pp. 187–194.

Sexton, Eithne, Mary-Ann O'Donovan, Niamh Mulryan, Philip McCallion, and Mary McCarron. "Whose Quality of Life? A Comparison of Measures of Self-Determination and Emotional Wellbeing in Research with Older Adults with and without Intellectual Disability." *Journal of Intellectual and Developmental Disability,* vol. 41, no. 4, 2016, pp. 324–337.

Sharp, Rebecca A., Oliver C. Mudford, and Douglas Elliffe. "Representativeness of Direct Observations Selected Using a Work-Sampling Equation." *Journal of Applied Behavior Analysis,* vol. 48, no. 1, 2015, pp. 153–166.

Shepherd, Victoria, Kerenza Hood, Mark Sheehan, Richard Griffith, and Fiona Wood. "'It's a Tough Decision': A Qualitative Study of Proxy Decision-Making for Research Involving Adults Who Lack Capacity to Consent in UK." *Age and Ageing,* vol. 48, no. 6, 2019, pp. 903–909.

Sigstad, Hanne M.H. "Characteristic Interviews, Different Strategies: Methodological Challenges in Qualitative Interviewing Among Respondents with Mild Intellectual Disabilities." *Journal of Intellectual Disabilities,* vol. 18, no. 2, 2014, pp. 188–202.

Sigstad, Hanne M.H., and Veerle Garrels. "Facilitating Qualitative Research Interviews for Respondents with Intellectual Disability." *European Journal of Special Needs Education,* vol. 33, no. 5, 2018, pp. 692–706.

Silva, Soraia M., Fernanda I. Corrêa, Gabriela S. Pereira, Christina Danielli Coelho de Morais Faria, and João C.F. Corrêa. "Construct Validity of the Items on the Stroke Specific Quality of Life (SS-QOL) Questionnaire that Evaluate the Participation Component of the International Classification of Functioning, Disability and Health." *Disability and Rehabilitation,* vol. 40, no. 2, 2018, pp. 225–231.

Simões, Cristina, and Sofia Santos. "The Quality of Life Perceptions of People with Intellectual Disability and Their Proxies." *Journal of Intellectual & Developmental Disability,* vol. 41, no. 4, 2016, pp. 311–323.

Singleton, Jenny L., Gabrielle Jones, and Shilpa Hanumantha. "Toward Ethical Research Practice with Deaf Participants." *Journal of Empirical Research on Human Research Ethics,* vol. 9, no. 3, 2014, pp. 59–66.

Siordia, Carlos, and Rebekah Young. "Methodological Note: Allocation of Disability Items in the American Community Survey." *Disability and Health Journal,* vol. 6, no. 2, 2013, pp. 149–153.

Siordia, Carlos, Lori A. Hoepner, and Allen N. Lewis. "Why Public Health Researchers Should Consider Using Disability Data from the American Community Survey." *Journal of Community Health,* vol. 43, no. 4, 2018, pp. 738–745.

Sitter, Kathleen C. "Participatory Video Analysis in Disability Research." *Disability & Society,* vol. 30, no. 6, 2015, pp. 910–923.

Skyrme, Sarah L., and Simon Woods. "Researching Disabled Children and Young People's Views on Decision-Making: Working Reflexively to Rethink Vulnerability." *Childhood,* vol. 25, no. 3, 2018, pp. 355–368.

Sleijser-Koehorst, Marije L.S., Lisette Bijker, Pim Cuijpers, Gwendolyne G.M. Scholten-Peeters, and Michel W. Coppieters. "Preferred Self-Administered Questionnaires to Assess Fear of Movement, Coping, Self-Efficacy, and Catastrophizing in Patients with Musculoskeletal Pain–A Modified Delphi Study." *Pain,* vol. 160, no. 3, 2019, pp. 600–606.

Smith, S. C., A. A. J. Hendriks, S. J. Cano, and N. Black. "Proxy Reporting of Health-Related Quality of Life for People with Dementia: A Psychometric Solution." *Health & Quality of Life Outcomes,* vol. 18, no. 1, 2020, pp. 1–10.

Soares, E. M., T. Granjo, S. Monteiro, S. Bemposta, and A. Salvador. "Accessible Communication in the Transport of Non-Urgent People with Communication Impairments." *European Journal of Public Health,* vol. 30, suppl. 2, 2020.

Sola-Valls, Nuria, Helena Arino, Domingo Escudero, Elisabeth Solana, Albert Llado, Raquel Sanchez-Valle, Yolanda Blanco, Albert Saiz, Josep Dalmau, and Francesc Graus. "Telemedicine Assessment of Long-Term Cognitive and Functional Status in Anti-Leucine-Rich, Glioma-Inactivated 1 Encephalitis." *Neurology Neuroimmunology & Neuroinflammation,* vol. 7, no. 2, 2020.

St. John, Brittany, Iulia Mihaila, Katelyn Dorrance, Leann S. DaWalt, and Karla K. Ausderau. "Reflections from Co-Researchers with Intellectual Disability: Benefits to Inclusion in a Research Study Team." *Intellectual and Developmental Disabilities,* vol. 56, no. 4, 2018, pp. 251–262.

Stack, Erin E., and Katherine McDonald. "We Are 'Both in Charge, the Academics and Self-Advocates': Empowerment in Community-Based Participatory Research." *Journal of Policy and Practice in Intellectual Disabilities,* vol. 15, no. 1, 2018, pp. 80–89.

Stack, Rebecca J., Christian D. Mallen, Chris Deighton, Patrick Kiely, Karen L. Shaw, Alison Booth, Kanta Kumar, Susan Thomas, Ian Rowan, Rob Horne, Peter Nightingale, Sandy Herron-Marx, Clare Jinks, and Karim Raza. "The Development and Initial Validation of a Questionnaire to Measure Help-Seeking Behaviour in Patients with New Onset Rheumatoid Arthritis." *Health Expectations,* vol. 18, no. 6, 2015, pp. 2340–2355.

Stancliffe, Roger J., Renáta Tichá, Sheryl A. Larson, Amy S. Hewitt, and Derek Nord. "Responsiveness to Self-Report Interview Questions by Adults with Intellectual and Developmental Disability." *Intellectual and Developmental Disabilities,* vol. 53, no. 3, 2015, pp. 163–181.

Stavrakantonaki, Marina, and Timothy P. Johnson. "Effects of Rosa's Law on Intellectual-Disability Reporting." *Public Opinion Quarterly,* vol. 82, no. 3, 2018, pp. 593–604.

Stevenson, Miriam. "Participatory Data Analysis Alongside Co-Researchers Who Have Down Syndrome." *Journal of Applied Research in Intellectual Disabilities,* vol. 27, no. 1, 2014, pp. 23–33.

Stokes, Jonathan, Christopher J. Evans, Farrah Pompilus, Alan L. Shields, and Kent H. Summers. "Development of a Questionnaire to Assess the Impact of Chronic Low Back Pain for Use in Regulated Clinical Trials." *The Patient,* vol. 6, no. 4, 2013, pp. 291–305.

Strnadová, Iva, and Jan Walmsley. "Peer-Reviewed Articles on Inclusive Research: Do Co-Researchers with Intellectual Disabilities Have a Voice?" *Journal of Applied Research in Intellectual Disabilities,* vol. 31, no. 1, 2018, pp. 132–141.

Strnadová, Iva, Jan Walmsley, Kelley Johnson, and Therese M. Cumming. "Diverse Faces of Inclusive Research: Reflecting on Three Research Studies." *Scandinavian Journal of Disability Research,* vol. 18, no. 1, 2016, pp. 52–64.

Strnadová, Iva, Therese M. Cumming, Marie Knox, and Trevor Parmenter. "Building an Inclusive Research Team: The Importance of Team Building and Skills Training." *Journal of Applied Research in Intellectual Disabilities,* vol. 27, no. 1, 2014, pp. 13–22.

Sunnquist, Madison, Savitri Lazarus, and Leonard A. Jason. "The Development of a Short Form of the DePaul Symptom Questionnaire." *Rehabilitation Psychology,* vol. 64, no. 4, 2019, pp. 453–462.

Swatt, Adam J., Ariel E. Schwartz, and Jessica M. Kramer. "Youth's Perspective of Responsibility: Exploration of a Construct for Measurement with Youth with Developmental Disabilities." *Physical & Occupational Therapy in Pediatrics,* vol. 39, no. 2, 2019, pp. 204–216.

Synnot, Anneliese, Sophie Hill, Michael Summers, and Michael Taylor. "Comparing Face-to-Face and Online Qualitative Research with People with Multiple Sclerosis." *Qualitative Health Research,* vol. 24, no. 3, 2014, pp. 431–438.

Takenoshita, S., S. Terada, R. Kuwano, T. Inoue, T. Kurozumi, A. Choju, S. Suemitsu, and N. Yamada. "Validation of the Japanese Version of the Dementia Screening Questionnaire for Individuals with Intellectual Disabilities." *Journal of Intellectual Disability Research,* vol. 64, no. 12, 2020, pp. 970–979.

Tarzia, Laura, Michael Bauer, Deirdre Fetherstonhaugh, and Rhonda Nay. "Interviewing Older People in Residential Aged Care About Sexuality: Difficulties and Challenges." *Sexuality and Disability,* vol. 31, no. 4, 2013, pp. 361–371.

Teachman, Gail, and Barbara E. Gibson. "Children and Youth with Disabilities: Innovative Methods for Single Qualitative Interviews." *Qualitative Health Research,* vol. 23, no. 2, 2013, pp. 264–274.

Teresi, Jeanne A., Katja Ocepek-Welikson, John A. Toner, Marjorie Kleinman, Mildred Ramirez, Joseph P. Eimicke, Barry J. Gurland, and Albert Siu. "Methodological Issues in Measuring Subjective Well-Being and Quality-of-Life: Applications to Assessment of Affect in Older, Chronically and Cognitively Impaired, Ethnically Diverse Groups Using the Feeling Tone Questionnaire." *Applied Research in Quality of Life,* vol. 12, no. 2, 2017, pp. 251–288.

Thurman, Whitney A., and Tracie C. Harrison. "Reaching the 'Hard-to-Reach': Recruitment of Rural-Dwelling Adults with Disabilities." *Journal of Transcultural Nursing,* vol. 31, no. 2, 2020, pp. 171–177.

Timmins, Fiona, Pearl O'rourke, Annamaria Bagnasco, Bernard Timmins, Ray Ekins, Siobhan Long, Giuseppe Aleo, and Loredana Sasso. "Using Videoed Workshops in Interdisciplinary Research with People Who Have Disabilities." *Nurse Researcher,* vol. 25, no. 2, 2017, pp. 24–28.

Tompke, Braden K., Jennie Tang, Irina I. Oltean, M. C. Buchan, Shannon V. Reaume, and Mark A. Ferro. "Measurement Invariance of the WHODAS 2.0 Across Youth With and Without Physical or Mental Conditions." *Assessment,* vol. 27, no. 7, 2020, pp. 1490–1501.

Trevisan, Filippo. "Making Focus Groups Accessible and Inclusive for People with Communication Disabilities: A Research Note." *Qualitative Research,* July 22, 2020.

Turnpenny, Agnes, James Caiels, Beckie Whelton, Lisa Richardson, Julie Beadle-Brown, Tanya Crowther, Julien Forder, Joanna Apps, and Stacey Rand. "Developing an Easy Read Version of the Adult Social Care Outcomes Toolkit (ASCOT)." *Journal of Applied Research in Intellectual Disabilities,* vol. 31, no. 1, 2018, pp. e36–e48.

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.

Valerio, Melissa A., Natalia Rodriguez, Paula Winkler, Jaime Lopez, Meagen Dennison, Yuanyuan Liang, and Barbara J. Turner. "Comparing Two Sampling Methods to Engage Hard-to-Reach Communities in Research Priority Setting." *BMC Medical Research Methodology,* vol. 16, no. 146, 2016, online only.

van den Broek, Martin D., Linda Monaci, and Jared G. Smith. "Personal Problems Questionnaire (PPQ): Normative Data and Utility in Assessing Acquired Neurological Impairment." *Archives of Clinical Neuropsychology,* vol. 34, no. 5, 2019, pp. 625–636.

Van Houtven, Courtney H., Steven J. Lippmann, Emmanuelle Belanger, Valerie A. Smith, Hailey J. James, Megan Shepherd-Banigan, Eric Jutkowitz, Emily O'Brien, Jennifer L. Wolff, James R. Burke, et al. "Measurement Properties of the CAPACITY Instrument to Assess Perceived Communication with the Health Care Team Among Care Partners of Patients with Cognitive Impairment." *Medical Care,* vol. 58, no. 9, 2020, pp. 842–849.

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,* 2019.

Vass, Caroline M., Niall J. Davison, Geert Vander Stichele, and Katherine Payne. "A Picture Is Worth a Thousand Words: The Role of Survey Training Materials in Stated-Preference Studies." *The Patient: Patient-Centered Outcomes Research,* vol. 13, no. 2, 2020, pp. 163–173.

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.

Verseghy, Judy, Lynda Atack, and Janet Maher. "Key Considerations When Interviewing Individuals with Expressive Language Difficulties." *Qualitative Research,* vol. 20, no. 6, 2020, pp. 960–970.

Viklund, Henrik, Birgitta Ausén, Göran Hagman, and Lisa B. Thorell. "The Executive Checklist (EC-10) – a New Rating Instrument for Clinicians Assessing Dysexecutive Behavior." *Applied Neuropsychology: Adult.* Published ahead of print, September 16, 2019.

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

Wager, J., F. Barth, L. Stahlschmidt, and B. Zernikow. "Testing the Validity of Telephone Interviews to Assess Chronic Pain in Children and Adolescents: A Randomized Cross-Over Trial." *European Journal of Pain,* vol.21, no. 10, 2017, pp. 1707–1716.

Walker, Lorraine O., Heather Becker, Erin E. Andrews, and Carolyn S. Phillips. "Adapting a Health Behavioral Change and Psychosocial Toolkit to the Context of Physical Disabilities: Lessons Learned from Disabled Women with Young Children." *Disability and Health Journal,* vol. 14, no. 1, 2021, online ahead of print.

Walmsley, Jan, Iva Strnadová, and Kelley Johnson. "The Added Value of Inclusive Research." *Journal of Applied Research in Intellectual Disabilities,* vol. 31, no. 5, 2018, pp. 751–759.

Wand, Benedict M., Mark J. Catley, Martin I. Rabey, Peter B. O'Sullivan, Neil E. O'Connell, and Anne J. Smith. "Disrupted Self-Perception in People with Chronic Low Back Pain. Further Evaluation of the Fremantle Back Awareness Questionnaire." *The Journal of Pain,* vol. 17, no. 9, 2016, pp. 1001–1012.

Ward, Bryce, Andrew Myers, Jennifer Wong, and Craig Ravesloot. "Disability Items from the Current Population Survey (2008–2015) and Permanent Versus Temporary Disability Status." *American Journal of Public Health,* vol. 107, no. 5, 2017, pp. 706–708.

Warden, Clara, Katherine Yun, and Wagahta Semere. "Using the Children with Special Health Care Needs Screener with Immigrant Families: An Analysis of the National Survey of Children's Health." *Journal of Immigrant and Minority Health,* vol. 21, no. 1, 2019, pp. 189–197.

Watchman, Karen, Kate Mattheys, Andrew Doyle, Louise Boustead, and Orlando Rincones. "Revisiting Photovoice: Perceptions of Dementia Among Researchers with Intellectual Disability." *Qualitative Health Research,* vol. 30, no. 7, 2020, pp. 1019–1032.

Weaver, Meaghann S., Rewais Hanna, Scott Hetzel, Karen Patterson, Alice Yuroff, Sarah Sund, Meredith Schultz, Mary Schroth, and Matthew A. Halanski. "A Prospective, Crossover Survey Study of Child- and Proxy-Reported Quality of Life According to Spinal Muscular Atrophy Type and Medical Interventions." *Journal of Child Neurology,* vol. 35, no. 5, 2020, pp. 322–330.

Wells, Stephanie Y., Jessica R. Dietch, Benjamin J. Edner, Lisa H. Glassman, Steven R. Thorp, Leslie A. Morland, and Gregory A. Aarons. "The Development of a Brief Version of the Insomnia Severity Index (Isi-3) in Older Adult Veterans with Posttraumatic Stress Disorder." *Behavioral Sleep Medicine*. Published ahead of print, June 1, 2020.

Wickenden, Mary, and Gayatri Kembhavi-Tam. "Ask Us too! Doing Participatory Research with Disabled Children in the Global South." *Childhood,* vol. 21, no. 3, 2014, pp. 400–417.

Wiley, Susan, and Jareen Meinzen-Derr. "Use of the Ages and Stages Questionnaire in Young Children Who Are Deaf/Hard of Hearing as a Screening for Additional Disabilities." *Early Human Development,* vol. 89, no. 5, 2013, pp. 295–300.

Williams, Toni L. "Exploring Narratives of Physical Activity and Disability Over Time: A Novel Integrated Qualitative Methods Approach." *Psychology of Sport and Exercise,* vol. 37, 2018, pp. 224–234.

Wilson, Carlee, and Esther S. Kim. "Qualitative Data Collection: Considerations for People with Aphasia." *Aphasiology,* November 18, 2019.

Wilson, Nathan J., Yu-Wei Chen, Natasha Mahoney, Angus Buchanan, Anne Marks, and Reinie Cordier. "Experience Sampling Method and the Everyday Experiences of Adults with Intellectual Disability: A Feasibility Study." *Journal of Applied Research in Intellectual Disabilities,* vol. 33, no. 6, 2020, pp. 1328–1339.

Wright-Bevans, Katie, Michael Richards, Mary Brydon-Miller, Michael Kral, and Alfredo Ortiz Aragón. "Using PAR to Promote Social Justice for Older People and People with Intellectual Disabilities." *International Review of Qualitative Research,* vol. 13, no. 2, 2020, pp. 219–232.

Wyman, Joshua D., Jennifer Lavoie, and Victoria Talwar. "Best Practices for Interviewing Children with Intellectual Disabilities in Maltreatment Cases." *Exceptionality,* vol. 27, no. 3, 2019, pp. 167–184.

Yang, Ming, Xiang Ding, and Birong Dong. "The Measurement of Disability in the Elderly: A Systematic Review of Self-Reported Questionnaires." *Journal of the American Medical Directors Association,* vol. 15, no. 2, 2014, pp. 150.e1–150.e9.

Zur, Oz, and Eli Carmeli. "The University of California Los Angeles Dizziness Questionnaire: Advantages and Disadvantages." *Journal of Vestibular Research,* vol. 23, no. 6, 2013, pp. 279–283.

This page has been left blank for double sided copying.

Mathematica

Princeton, NJ • Ann Arbor, MI • Cambridge, MA
Chicago, IL • Oakland, CA • Seattle, WA
Tucson, AZ • Woodlawn, MD • Washington, DC

EDI Global, a Mathematica Company

Bukoba, Tanzania • High Wycombe, United Kingdom

Mathematica
Progress Together

mathematica-mpr.com