

The 1994-1995 National Health Interview Survey on Disability (NHIS-D): A Bibliography of 20 Years of Research

Brian Ward, PhD

National Center for Health Statistics, USA,

Heather Ridolfo, PhD

U.S. Department of Agriculture, USA,

Lauren Creamer

University of Maryland, USA &

Caroline Gray, PhD

Palo Alto Medical Foundation, USA

Abstract: The 1994-1995 National Health Interview Survey on Disability (NHIS-D) has been one of the most unique and important data sources for studying disability, impairment, and health in the United States. In celebration of the NHIS-D's twenty-year anniversary, we created an extensive bibliography (n=212) of research that has used these data.

Key Words: National Center for Health Statistics; National Health Interview Survey on Disability; NHIS-D

In the 1990s, the United States implemented the Americans with Disabilities Act (ADA) and other policies to deter discrimination against persons with various types of disabilities (Hendershot, Larson, & Lakin, 2003). An outcome of these policies was that both private businesses and public organizations were met with new requirements to increase accessibility and fair treatment of individuals with disabilities. As with the implementation of any new policy, the need for quantitative data to monitor the effects of these policies, and the resulting experiences of the individuals they impact, became apparent. With no readily-available dataset to meet these needs, four U.S. Federal agencies collaborated to design and implement a nationally-representative survey. The end result was a survey supplement that accompanied the 1994-1995 National Health Interview Survey (NHIS), referred to as the National Health Interview Survey on Disability (NHIS-D) (Hendershot et al., 2003; Simpson, Keer, & Cynamon, 1992).

Over the past twenty years there have been numerous sources of data used to study disability, impairment, and health in the United States. However, of these data sources the NHIS-D has arguably been one of the most unique and important. First, it contains a variety of measures that can be used as indicators of impairment and functional and role limitations (Altman & Rasch, 2003). Second, with multiple agencies involved in determining its content, its data covers a wide array of topics that can be empirically examined. Finally, it is also a nationally-representative dataset that allows broad generalization, and generalization to more specific subpopulations (e.g., children with special health care needs, families with a member who has a disability). While the NHIS-D also has its limitations (Altman & Rasch, 2003), these have not outweighed its strengths. As evidence of its importance, peer-reviewed research that uses the NHIS-D is still being published, and the National Center for Health Statistics (the agency that conducted the NHIS-D) still receives questions and comments from its data users inquiring if and when another version of the NHIS-D will be designed and implemented. Although another version has not been implemented, in response to what has been learned from

the NHIS-D a number of survey questions asking respondents about impairment and limitations have since been added to the NHIS and are included annually on the survey.

In celebration of the NHIS-D's twenty-year anniversary, we created an extensive bibliography that is comprised of research that has used these data. The purpose of this bibliography was to not only serve as a resource for those wishing to identify studies that have used data from the NHIS-D, but also document the vast amount of knowledge the field of disability studies has gained through this survey supplement.

We constructed this bibliography by conducting a systematic literature search that identified manuscripts which utilized, discussed, and/or analyzed data from the NHIS-D. Nine terms were used as keywords in the search, which included: (1) National Health Interview Survey on Disability, (2) NHIS-D, (3) NHIS on Disability, (4) National Health Interview Survey Disability Supplement, (5) NHIS Disability Supplement, (6) National Health Interview Survey Disability Followback, (7) NHIS Disability Followback, (8) National Health Interview Survey Disability Component, and (9) NHIS Disability Component. Both the terms *National Health Interview Survey Disability Followback* and *NHIS Disability Followback* were also searched using the two alternative spellings: "Follow Back" and "Follow-back." Searches for these keywords were performed in three databases (Google Scholar, PubMed, and Web of Science) for the years 1990-2013, and concluded in January 2014. Although the NHIS-D was not conducted until 1994, the preceding four years were included in the search to ensure any manuscripts published on the methodology, planning, and/or implementation of the NHIS-D were captured.

Our search yielded 256 manuscripts that were initially identified as having used the NHIS-D. The types of manuscripts included were books, book chapters, peer-reviewed journal articles, brief and full-length research reports, doctoral dissertations and master's theses, and conference proceedings. We omitted any abstracts from conferences that appeared in our search results which were not part of a complete proceedings paper. Each of these manuscripts was subsequently obtained and reviewed in detail, and any study that did not utilize, discuss, and/or analyze the NHIS-D data was removed (44 manuscripts).

The final result of our literature search was a total of 212 manuscripts that were included in the proceeding bibliography. As the NHIS-D was designed to ask questions on a broad range of topics, the focus of these manuscripts encompass research on numerous subjects including (but not limited to) the use of assistive devices, work/employment and disability, children with special health care needs (CSHCN), caregiving, the relation of chronic conditions and disability, access to care and service utilization by individuals with disabilities, and even survey methodology. Collectively, this large number of manuscripts, and the plethora of topics they investigate, exhibits the sustained usefulness of the NHIS-D over the past twenty years and the vast amount of knowledge that has been added to the field of disability studies by this survey supplement. We hope this extensive bibliography will encourage researchers to continue to use the NHIS-D and its resulting publications to generate new knowledge that may further advance our understanding of disability and impairment.

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Brian W. Ward, PhD, earned his doctorate in Sociology from the University of Maryland. He is currently a health statistician at the National Center for Health Statistics.

Heather Ridolfo, PhD, earned her doctorate in Sociology from the University of Maryland. She is currently a survey statistician at the U.S. Department of Agriculture.

Lauren Creamer is an undergraduate student at the University of Maryland where she is earning her BA in Sociology.

Caroline Gray, PhD, earned her doctorate in Sociology from Yale University. She is currently a senior qualitative research associate at the Palo Alto Medical Foundation.

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