PIRL Protocol for Review of "Asking about Disability in Research"

Adapted from the PRISMA-P Guidelines. Moher D, Shamseer L, Clarke M, Ghersi D, Liberati A, Petticrew M, Shekelle P, Stewart LA. Preferred Reporting Items for Systematic Review and Meta-Analysis Protocols (PRISMA-P) 2015 statement. Syst Rev. 2015;4(1):1.

This paper describes in detail the process used for the narrative review **Titled**: Considerations when asking about "disability" in Disability Inclusive Development Research

Identification Number Not Applicable

This is the protocol for a narrative review conducted by the **Partnerships for Inclusive Research and Learning (PIRL) Project**. This protocol is an update of a previously developed, unpublished protocol for this study. There is no registration number for this protocol.

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Contributions of authors

All authors were part of substantially conceptualizing the review, reviewing and analyzing articles, writing sections of the final paper, and reviewing and editing the final manuscript. All authors read and approved the final version of the paper and have agreed to be accountable for all aspects.

LC, NH, AK, SL provided initial drafts of the work and reviewed it critically throughout the development of the final paper. LC developed the methodology, led the formal analysis, provided supervision and project administration. LC, JN, LM acquired the financial support for the project leading to this publication.

Guarantor: Lynn Cockburn

Amendments: There have been no amendments made to this protocol. At the time of publication of this protocol, July 2023, we do not have a documented plan for important protocol amendments.

Introduction

Rationale

"Disability" is a complex concept with multiple meanings (Federici et al., 2017; Kuper et al., 2020; World Health Organization & World Bank, 2011). Its definitions vary greatly worldwide due to differences in social and cultural factors intertwined by context-driven intersectionality (Acker-Verney, 2016; Carbado et al., 2013; Horner-Johnson, 2021; Kirichenko & Król, 2022). These nuances create challenges for researchers when determining an appropriate approach to define and ask about disability, particularly when conducting disability inclusive research within multinational settings.

Despite the plethora of literature on several types of disability tools published there is a perceived lack of useful resources and tools on how to carefully consider the inclusion of questions and analysis about disability in research. This review is part of efforts to address this gap.

Objectives of the review

This review will focus on methods **used in research**, and to share understandings on how to ask about "disability" in research studies (surveys, interviews, and other development-oriented research studies), especially in intersectional work that spans international and global contexts. This introductory explanatory methods overview paper will make comparisons between different frameworks and approaches for understanding the concept of disability in research work. It will provide a narrative overview of how disability can be addressed in data collection in research.

Methods

Eligibility criteria

We are interested in both recent and earlier foundational studies and reports that assist with understanding the approaches to asking about disability in research.

Study characteristics to be used as criteria for eligibility for the review

The team decided on using a narrative review process due to the nature of our questions, which did not have hard boundaries. We used the PRISMA-P reporting guidelines to develop this protocol to guide the process (Moher et al., 2015).

All intended information sources

We will use electronic databases available through the U of Toronto library and Google Scholar. We will not contact study authors or trial registers for additional information. We will use recent websites related to the tools that are identified, such as the World Health Organization (WHO) and the Washington Group.

Search strategy

This is the proposed search strategy to be used for the electronic databases, including planned limits, such that it could be repeated.

Previous work has identified 6 commonly used approaches that will be used to search the literature and for inclusion in this study. The Databases to be searched are: Google Scholar, Pub Med, EBSCO, CINAHL, SCOPUS, MEDLINE, EMBASE, Sociological Abstracts, and Web of Science.

In general, we will use two sets of search terms. The first set is to broadly identify work related to our topic. Keywords are 1) disability or disab* and 2) research methods and 3) measurement tool.

The second set is specific to the approaches we identified in the process of preparing this review and will add any new approaches if they are identified. For this set the search terms are [Name of Approach e.g. "Washington Group"] AND Research methods OR Disability.

These terms are:

- The International Classification of Functioning, Disability and Health (ICF)
- World Health Organization Disability Assessment Schedule (WHODAS)
- Washington Group [Questions]
- Demographic and Health Surveys (DHS) - Disability Module
- Model Disability Survey (MDS)
- Rapid Assessment of Disability (RAD)
- Direct Question – "Asking about disability in research"

If the number of search results is over 500 in a database, we will narrow to a list of ~100 articles using available filters, such as to the most recent 10 years, more specific subject terms, and so on. Alternatively, if the results can be organized by relevancy or date, the researcher could decide to take the first 100 that are most relevant or recent.

This strategy of using several databases and search engines will lead to a good list of key articles about the approaches, and a very representative sample of studies that have used them. No date limits will be used, however we will give preference to studies that are either foundational studies (e.g. about how an approach was developed) or good examples from the past 5 years. The reference lists of key papers meeting inclusion criteria may be reviewed for other potentially eligible studies.

We will delete duplicates.

This search strategy will result in a robust list of articles that can be used for our study.

Study records - data management

To manage records and data throughout the review, RIS (Research Information Systems) and other document formats will be imported into the Zotero library (*Zotero*, 2023)and Covidence (*Covidence*, 2023). Soft copies of included documents and articles (usually PDFs) will be kept on laptops/computers of the team members, and in shared folders.

Citations and pdfs of the studies will be loaded into Covidence for review and information extraction.

Study records - selection process

The process that will be used for selecting studies has been developed by the research team to meet the goals of the project. At least 2 members of the research team will review the list of possible articles in Covidence to identify 1) key articles and resources describing the use of each approach, and 2) examples of each approach, generally from within the past 5 years.

Using the PRISMA process and the Covidence application, titles and abstracts of studies will be screened for the first stage of inclusion by one author. Any questions or conflicts will be resolved by at least 2 authors. Full texts of each included article will be reviewed by at least one author.

The section for each approach will be written by at least 2 members of the team and reviewed by other members of the team. Articles selected for inclusion will be moved to the information extraction phase. The literature search and review process will stop when the writing team has considered all initially identified articles and determined a sufficient number of articles for each section.

Study records - data collection process

Data will be collected from each resource using the Data Extraction form in Covidence, which has been specifically set up for this project. It has been piloted with team members. Data will then be exported to an excel data sheet for additional analysis. The data collection template is available on request from the authors.

Included articles will be compiled into a final list.

Data items

Specific variables such as PICO items, funding sources, or geographic locations are not included because they are not relevant to this review. The team will be open to any relevant articles that support the purpose of the review. We are assuming that a range of example studies will provide illustrative information that can be used.

Outcomes and prioritization

The inclusion of persons with disabilities is an important outcome in research studies. Too frequently persons with disabilities are either explicitly excluded from research or not even considered and disability disaggregated data then is not available (Abualghaib et al., 2019). The primary outcome we are searching for is how researchers have included questions and data collection related to disability (broadly speaking) in their studies.

The outcomes in the data extraction form have been deliberatively kept brief to allow for rapid review in Covidence. For articles that will be summarized, we will extract the following information:

- **General information**: Title of paper / abstract / report that data are extracted from; Lead author contact details; Country/ies in which the study took place
- **Disability approach used:** ICF, WHO DAS, Washington Group Short Set, Washington Group Long Set, Washington Group Short set 8 questions, Washington Group Children, Direct question, Survey, Other
- **Type of article**: Methods - It gives specific directions; Research study - it uses one or more approaches in the study; Review - Systematic or scoping; Review - Narrative, social sciences
- **Purpose and Methods of the study**: Aim of study; Study design (e.g. Qualitative research; Randomised controlled trial, case report); Key comments relevant for our review

Risk of bias in individual studies

Assessing risk of bias is not relevant in this review.

Data synthesis - Quantitative

We are not going to do any quantitative synthesis of data, so this category is not applicable.

Data synthesis

This section describes the type of summary planned.

We will use a narrative literature review approach to conduct this study (Dixon-Woods et al., 2005; Greenhalgh et al., 2018). To develop our research methods, we drew from narrative review, systematic review, and systematic methods review literature, particularly the approach by Gentles and colleagues (Gentles et al., 2016) which discusses ways to review research methods. The details of the phases, principles, and strategies used in the current paper will be summarized in the final paper, adapted from Gentles et al (2016).

We will aim to search for, describe, and interpret the relevant literature to achieve our review objectives. The aim in methods overviews is to seek coverage of the qualitative concepts relevant to the methods topic of interest; in this case, our aim is to provide a narrative overview of how disability can be addressed in data collection, particularly in research. Since we are not going to conduct a quantitative systematic review and there are potentially hundreds of thousands of articles describing disability in research, the exact numbers of articles found will not be an crucial aspect of what will be recorded. We will however, have estimated numbers for each of the databases we search, and for the articles entered into Covidence for review.

Analysis will start with the process of identification of studies to include. As we identify peer-reviewed research articles, we will summarize the most authoritative and influential approaches, definitions, and meanings for methods-related concepts of disability for use in research. We will also include non-peer reviewed documents and reports such as research guidebooks and websites, as these can be very informative to answer our research questions. We will select and record examples of both effective use of approaches, and where there was a problematic lack of clarity in how impairment or disability was defined or included in the study.

Analysis will continue with the selection of papers, as we take two roads – analysis of methods papers and analysis of example studies. We will include

these two kinds of documents to understand the details of methods used when asking about disability. The first type are methods papers which specifically focus on *how* to do research. Included articles will be published approximately between 2000 to June 2023, but earlier papers will be included if they are deemed very influential and important for understanding the history of the approach. These articles will be used to provide an overview of the directions provided on how to use widely established methods-related concepts (i.e., WHO-DAS and the Washington Group approaches).

The second type to be included will be recent research papers which used the various methodological approaches identified from the first group of articles. Since our interests are in current applications, articles published between January 2017 to July 2023 (6.5 years) will be included. Papers providing recent examples on the various approaches particularly in the methods, discussion, and recommendations sections will be screened for pertinent examples. These methods-relevant sections of empirical study reports will illustrate how the concept of disability was operationalized in research practice and how they were reported by authors.

We will purposely include high impact journals and papers in disability studies, rehabilitation, public health, medicine, and social sciences to describe how researchers implemented these methods. For these high impact papers, we will have a loose cap of about 100 papers due to our limitations of time and resources to conduct the review. We also want to have wide geographic coverage, so we will purposely look for and include articles from all regions and continents to ensure that the representation was global, even if they are not high impact, especially for the areas that did not have a lot of publications. This will lead to a second group of about 100 articles to draw from.

As described above, searches will be conducted using the University of Toronto library system, Google Scholar, websites, and the WHO websites to identify relevant documents and reports during July 2023. If necessary, we will return to the literature to identify additional documents in both categories (methods papers and methods-relevant papers). We will also use current papers or other documents (e.g., websites) for descriptions of each approach.

Analysis will continue as members of the writing team write summaries and sections of the paper. The PIRL Project team consists of members with a wide range of research experiences, from student to experienced researchers. In writing these summaries and sections, we will pay careful

attention to the language used to describe disability and related concepts. Given that there is variation across publications and within fields, we want to understand how researchers asked about disability in their studies.

Our preparation for this review has indicated that there is a clear recognition that "one size does not fit all" when understanding disability in research studies. Therefore, we will identify key points to make recommendations for preferred approaches and methods for different types of research. For example, student projects with limitations in time and experience might have different needs and goals than large scale funded projects with many team members. Critical and theoretical projects will be different than quantitative surveys, and so on.

We will consider how different methodologies lead to a range of understandings of disability. For example, a methodology with dichotomies and binaries (either disabled or not disabled; blind or not blind) alter the disability ontology. These types of approaches, while having other advantages, reduce and limit nuances in understanding disability, and therefore understandings in disability research. The pressure to have one number, (for example, "the percentage of disabled people in the population is *X")*, is very tempting for many studies, but can also be misleading, contentious, and have real implications in subsequent programs and areas. The analysis will address these different voices in disability research.

Meta-biases

We are not conducting any planned assessment of meta-bias(es) (such as publication bias across studies, selective reporting within studies)so this section is not applicable.

Confidence in cumulative evidence

The strength of the body of evidence will not be assessed using a predefined process such as GRADE. We anticipate that confidence in the results will in part be evident by the number of duplicate articles that are identified, and by the expertise of the reveiwers. Other measures of confidence will not be used.

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