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"Nothing about us without us!": Representation and Participation in Human Rights-Based Research

Abstract

This article provides theoretical thoughts and practical insights concerning a human rights-based approach in the context of disability research. The author reflects on their experiences within a human rights-based research project on the participation of Organisations of Persons with Disabilities (OPDs) in policies and programs, as conducted by the International Disability Alliance (IDA) in partnership with the Assisting Living and Learning (ALL) Institute at Maynooth University, Ireland. Scrutinizing this research, this article makes evident both challenges and limitations inherent to it. Moreover, it points out good practices for achieving participation and representation of the diversity of disability constituencies in research—building on the disability rights movement's motto, "nothing about us without us" (cf. Charlton, 1998). This article is published in English because the author carried out their research project at Maynooth University in English. Deciding in favour of an English-language article has also increased transparency in negotiating agreement with the IDA on content, prior to publication.

Keywords: human rights-based research, disability studies, accessibility, representation

„Nichts über uns ohne uns!": Repräsentation und Partizipation in menschenrechtsbasierter Forschung

Zusammenfassung

Dieser Beitrag liefert theoretische Überlegungen und praktische Erkenntnisse zum menschenrechtsbasierten Ansatz in den Disability Studies durch die Reflexion eines Forschungsprojekts zur Beteiligung von Organisationen von Menschen mit Behinderungen an Politiken und Programmen, welches von der International Disability Alliance (IDA) in Zusammenarbeit mit dem Assisting Living and Learning (ALL) Institute/ Maynooth University durchgeführt wurde. Der Artikel zeigt sowohl Herausforderungen und Grenzen als auch bewährte Praktiken auf, um die Teilhabe und die Repräsentation einer Diversität an Gruppen von Menschen mit Behinderungen in der Forschung zu erreichen—ganz nach dem Motto der Behindertenrechtsbewegung „Nichts über uns ohne uns!" Der Beitrag wurde auf Englisch verfasst, da die gesamte Forschungsarbeit auf Englisch stattfand. Diese Entscheidung hat zudem die Transparenz in der Abstimmung des Artikels mit IDA vor Veröffentlichung erhöht.

Schlüsselwörter: menschenrechtsbasierte Forschung, Disability Studies, Barrierefreiheit, Repräsentation

1.Introduction to Human Rights-Based Research Approaches

This chapter introduces the main principles of a human rights-based research approach. This approach first attained a distinctive character in the 1960s, and was then mainly implemented by the human rights movement, including international nongovernmental organisations, and partly connected to international law research (cf. University of Michigan, n.d; Arstein-Kerslake et al., 2020). But only in recent years have human rights-based approaches to research has been conceptualized specifically for research on disability (Arstein-Kerslake et al., 2020, p. 417; Arstein-Kerslake et al., 2019, p. 590). It is based on emancipatory (cf. Barnes, 2005; Stone, Priestley & Stone, 1996), participatory (cf. Balcazar et al., 1998; Zarb, 1992; Zuber-Skerritt, 2001) and inclusive methodologies of disability research (cf. Johnson & Walmsley, 2003). It uses principles from those methodologies, wherever those are in line with the human rights model of disability. Human rights build the framework of the human rights model to research, and the structure to guide research design and objectives (Arstein-Kerslake et al., 2020, p. 413, 422; Arstein-Kerslake et. al., 2019, p. 590). Human rights-based research uses the “power and structure of human rights law to contribute to the realization of the full range of rights” of persons with disabilities (Arstein-Kerslake et al., 2020, p. 423).

The human rights model of disability, as established in the United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD),[1] builds the basis for this research. In consequence, human rights-based research emphasizes that the removal of social barriers, rather than individual impairments, should be at the heart of research and other work concerning disability (Arstein-Kerslake et al., 2020, pp. 415–416). Not only this model of disability, but also further principles and requirements of the CRPD guide the human rights-based research process.

Among comparable publications, the Disability Human Rights Research Network (DHRRN, 2018) outlines several implications for human rights-based research norms and goals that can be derived from the principles enshrined in the CRPD (see also Arstein-Kerslake et al., 2020, pp. 425–429). These include:

1. Human rights-based research applies a social and human rights-based model of disability and is free from paternalism (in line with the CRPD preamble and Articles 1–3).
2. Human rights-based research promotes equality (in line with CRPD Articles 4–5).
3. Human rights-based research challenges and confronts marginalising cultural attitudes (in line with CRPD Articles 5 and 8).
4. Human rights-based research design, implementation, and dissemination processes are accessible and inclusive (in line with CRPD Articles 9 and 21).

Participatory principles guide human rights-based research, as mentioned above. In line with thoughts of Sherry Arnstein (1969) and Wright, Block, and von Unger (2010), levels of (non-)participation can be described on a continuum ranging from non-participation (also referred to as manipulation or instruction), via preliminary stages of participation (informing, consultation, and placation), and finally to degrees of power held by persons with disabilities (partnership, delegated power, and decision-making power). This continuum can even extend to stages beyond participation such as control and self-organisation of persons with disabilities. Human rights-based research involves persons with disabilities as partners or even gives them decision-making power throughout the research process.

The following paragraph details how these principles were applied in the research process around the IDA’s *2nd Global Survey* on OPD participation (IDA, 2022).

2. Global Survey on OPD Participation: Human Rights-Based Research in Practice

In 2021, IDA carried out the *2nd IDA Global Survey* on OPD participation in collaboration with ALL Institute, and with the involvement of this paper's author. It is based on the 2018 *1st Global Survey* which IDA[2] had launched to periodically review the global perception of OPDs regarding their own political participation in policies and programs, plans and projects with governments, regional organisations, funding agencies and the UN (IDA, 2018).

In the process of creating the *2nd Global Survey*, a wide range of participatory methods was applied during the different steps of research (Black, 1999, p. 27), as described in the following.

IDA initiated the research as a response to the voices of the community of persons with disabilities. The research is responding to a rights concern which was identified by IDA and its members. The exact research questions and objectives were developed in partnership between IDA and ALL Institute. The research design and implementation were led and guided mainly by IDA, in partnership with ALL Institute, and after considering voices of IDA's members, considering the wide range of different constituencies as well as intersectionality.

The planning stages of the research project were fully led by IDA, including writing funding proposals to different donors. The ethical protocol for this research was written by ALL Institute after consulting IDA and considering remarks for improvement. The research team was selected by IDA based on proposals from universities, and applications for a PhD and fellowship post for researchers to work closely on the Global Survey. Existing literature on the research topic was reviewed by this paper's author after consulting IDA.

IDA collected data using an accessible survey platform called iData, which had been tested and improved with a diverse group of people from IDA's member organisations to make sure it includes a wide range of accessible features that respond to a variety of preferences. 79 people, including 84% persons with different disabilities, 50% women and 40% from underrepresented groups tested the tool with different software programs, and varying preferences concerning connectivity, languages, and other accessibility requirements. Amongst others, the text of the survey was converted into plain language with self-advocates with intellectual disabilities who also validated an easy-to-read (cf. Inclusion Europe, n.d.) version of the questionnaire. The survey was also published in a wide range of different languages, and it was translated into International Sign. The data processing and analysis was done by the main researcher in consultation with IDA. IDA strongly supported the interpretation of data.

The scholarly documentation of the work (in form of write ups for the university and publications) was done mainly by the PhD researcher from ALL Institute but wherever wished in partnership with IDA. The documentation of the research report for advocacy of IDA was written by IDA in partnership with ALL Institute. Research outcomes and data were produced in accessible formats in partnership as well, and the involvement of agents for change from side of IDA and its members helped to translate the research findings into action.

The main researcher from ALL Institute improved the methodology of the research undertaken in partnership with IDA to inform the ongoing and subsequent steps in frame of the research process (e.g., *3rd Global Survey* to be implemented in 2023/2024). IDA independently draws conclusions from the undertaken research for future endeavors.

To summarise the participatory influence of the disability community in the presented research project, mediated through IDA, the table below shows in blue and green where the above-described process met standards of participatory research, and in yellow where it lived up to preliminary stages of participation only.

Research stages		**Level of participation of persons with disabilities**			
		Preliminary stages	Degress of power		Beyond participation
		Consultation	Partnership	Decision-making	Control & self-organisation
Planning and preparation	Initiating the research process				✓
	Identifying the problem & developing the topic				✓
	Reviewing literature and background information	✓			
	Planning research project and writing proposal				✓
	Selecting research team			✓	
	Determining research question, objectives and hypotheses		✓		
Research design and methodology	Developing research design and choosing methods		✓		
	Writing ethical proposal	✓			
Data collection and analysis	Collecting data				✓
	Processing and analysing data	✓	✓		
Documentation, communication and future development	Documenting the work and writing the report		✓	✓	
	Communicating findings				✓
	Refining, expanding and pioneering for future research		✓		✓

Tabel 1: Level of participation of persons with disabilities in the different research stages.

3. Limitations and Good Practices Experienced

This chapter gives an insight into challenges and good practices associated with implementing a human rights-based approach to research of the presented research project.

It was not always easy to adhere fully to the high standards and principles of this type of research. Limitations mainly stem from questions of resource availability and ethical requirements. A few examples are given below:

- Ethical standards from Maynooth University in parts slightly limited consideration of all voices, namely the one of youth respondents to the *2nd Global Survey*, limiting the results to those above the age of 18. In future iterations of this survey, this is a point to look at to ensure that the important voices of youth with disabilities are heard.

- Due to financial constraints, it was challenging at times to guarantee accessibility of the Global Survey for all research participants when it comes to language versions of the survey in easy-to-read and standardised formats. This has potentially left behind certain groups, e.g., at a grass-root level, or persons with a learning impairment or an intellectual disability who do not speak or read English.

- Representation of researchers with disabilities amongst the core research team was limited to a single research fellow, however all views and conclusions were guided by IDA. The difficulty to identify researchers with disabilities meeting the requirements for research of this dimension, despite proactive attempts and accommodation, partly reflects the levels of discrimination still faced by persons with disabilities in accessing higher education opportunities, particularly in the Global South.

- Despite the efforts to life up to the high standards of transparency, accountability and participation throughout the process, the research was not always free of challenges related to the "mediated participation" through IDA as well as the involvement of an "external" research institution. The process to come up with the research instrument used for the *2nd Global Survey* was not shared at each stage with IDA`s members, as it built upon a pre-existing instrument from the *1st Global Survey*, whose questionnaire was commented by the IDA Board. As different individuals were involved, this led e.g. to challenges and lack of satisfaction of some constituencies when designing an easy-to-read version of the pre-existing complex and long survey questionnaire.

Notwithstanding these challenges and limitations, the research process has made it possible to follow the emancipatory and participatory goals that guide human rights-based research. Some good practices that can be highlighted in this sense, and in addition to the ones outlined above, are as follows:

- IDA was strongly involved in a leading role in all stages of the data-collection exercise and had the required funding through different donors to do so; this has not least resulted in a survey platform that is specifically adapted to the diverse requirements of the diversity of constituencies and under continuous improvement based on feedback received from IDA´s members.

- Due consideration was given to the question of consent to participate in the research process and towards guaranteeing the privacy and confidentiality of personal information and responses shared in the *2nd Global Survey*. In line with this, survey participants were given the option to decide freely whether they would like to disclose personal characteristics, such as a disability. Moreover, IDA and its members were strongly involved in defining wording related to those disability groups who were addressed through the survey, and who were used to disaggregate data.

- The research itself became a tool for advocacy and social change as outputs promote social change required to meet the rights and obligations of the CRPD. IDA may use the results from the conducted survey in the wider context of a range of events, including Global Disability Summits and the Conference of State Parties to the CRPD.

- In line with the human rights-based research principles of transparency and accountability, data were collected in an accessible manner and collected on different constituencies. All collected data can be disaggregated to allow for the identification of inequalities amongst groups and considering intersecting forms of discrimination. Moreover, in line with these principles, research outcomes and data were published in accessible formats and disseminated through events designed to support the advocacy of OPDs who contributed to this research, for example towards greater engagement with the UN system.

As this article showed, the potential challenges and limitations of participatory research should not diminish existing good practices and opportunities of this kind of research. The participation and representation of the diversity of disability constituencies in research can make a great contribution to achieving the disability rights movement’s motto, “nothing about us without us", also in the academic realm.

Endnotes

[1] United Nations. (2006). *Convention on the Rights of Persons with Disabilities and Optional Protocol to the Convention on the Rights of Persons with Disabilities* (A/61/611). Adopted by the General Assembly on 6 December 2006.

[2] The International Disability Alliance (IDA) is a global network of organisations of persons with disabilities (OPDs), representing persons with disabilities worldwide.

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