

Title: Understanding how children and young people with disabilities experience COVID-19 and humanitarian emergencies in low- and middle-income countries: a scoping review protocol

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Abstract

Introduction

People with disabilities have been disproportionately affected by the COVID-19 pandemic and there is a need to understand the diversity of experience globally to plan and implement responses. The experience of children and young people with disabilities is often overlooked as research focuses on younger children or adults, and they are not often engaged in the design of research methods to capture their experience. As part of a research project to develop participatory methods with children and young people with disabilities in rural Nepal to research their experience of COVID-19 (PARDAN), we sought to map the literature about experiences of children and young people with disabilities in emergency and COVID-19 contexts, and describe the methods used. This review will inform the development of our methods and will help identify gaps in the literature.

Methods

We will use Arksey and O'Malley's (1) and Levac et al's (2) framework to search for grey and published literature. We will search Scopus, Web of Science, ASSIA, Jstor, Source, Google Scholar, Academia.edu, Researchgate, and Google. We will also search websites of organisations working in emergencies such as United Nations High Commissioner for Refugees (UNHCR), World Health Organisation (WHO), United Nations Children's Fund (UNICEF), Humanity and Inclusion (HI), CBM International, International Disability Alliance (IDA), Women's Refugee Commission (WRC), and National Federation of the Disabled Nepal (NFDN). We will approach our advisory committee and personal contacts in disabled persons organisations in the global south to help us locate additional relevant grey literature. Predetermined inclusion and exclusion criteria will be applied by five reviewers to determine study eligibility. Studies published in English and Nepali and between May 2011 and May 2021 will be reviewed. Methods and findings from literature will be extracted and a descriptive summary will be presented to an advisory committee of disabled persons organisations in Nepal.

Discussion

Through this review we will identify research gaps and develop implications of our findings which will be presented in a webinar and in publications. The review will be an important resource for

those seeking to conduct research about children and young people with disabilities and will inform a global inclusive response to the pandemic which includes the perspectives of children and young people.

Introduction

People with disabilities have been disproportionately affected by the COVID pandemic through increased risk of mortality and morbidity; increased discrimination and decreased access to care and services; and through the psychological and socio-economic consequences of the pandemic and efforts to bring it under control (3,4) This continues the trend of people with disabilities being disproportionately affected by the impacts of humanitarian emergencies through loss of mobility and increased dependency, psychological distress, and high rates of abuse, as well as often falling through the cracks in humanitarian response and struggling to have adequate access to basic assistance(5,6). Intersecting vulnerabilities of disability, low socio-economic status, marginalisation and age indicate that children and young people with disabilities have been uniquely affected and the pandemic has exacerbated existing inequalities (7,8).

To understand the unique effects of the pandemic, engaging children and young people with disabilities in the design of tools and methods can help ensure that data collection is non-discriminatory, age-appropriate, inclusive, and recognizes the rights and competencies of children and young people with disabilities (9,10). children and young people with disabilities participation in research enables the development of inclusive responses and recovery plans (11–13) but researchers and agencies can be reluctant to involve children and young people with disabilities in research. Researchers are often concerned about difficulties in access, communication, protection and ethical concerns, and they may underestimate children and young people with disabilities capacity to participate (14). There is a lack of training and guidance on best practices (15) which can result in caregivers often representing the experience of children and young people with disabilities (for example (16,17). Data collection with children and young people with disabilities in emergency situations in LMICs has unique challenges, and mobile data collection techniques may not be suitable or available which can exacerbate difficulties in reaching this group (18,19).

This scoping review is part of a research project in rural Nepal to understand children and young people with disabilities experience of COVID-19 (PARDAN), and to develop and disseminate methods to increase their inclusion in research and participation in pandemic recovery and response planning (20).Our objective is to inform the design of data collection methods to conduct inclusive participatory qualitative research with children and youth with disabilities and to inform our recommendations for understanding the experience of children and young people with disabilities in this and other crises.

Methods

We will follow the stages in the Arksey and O'Malley framework (1) and are informed by recommendations on this framework by Levac et al (2). We used the PRISMA checklist to develop this protocol.

Stage 1: Identifying the research questions

Our preliminary review of the literature revealed very little peer-reviewed evidence about the effect of COVID-19 on adolescents with disabilities. Grey literature did not always refer to

empirical data and when data were collected, the methods were often unclear. Given this lack of literature we broadened our search to collate evidence and methods from humanitarian emergency contexts. Our research questions are: 1) How have children and young people with disabilities experienced large-scale humanitarian emergencies (including disease outbreaks (e.g. COVID-19), natural disasters (e.g. earthquakes), and conflict) in low and middle income countries and 2) what research methods and tools have been used to research these experiences?

Stage II: Identifying relevant studies

A systematic search of published and unpublished literature describing the experiences of children and young persons with disabilities during the COVID-19 pandemic and humanitarian emergencies will be conducted. We will search Scopus, Web of Science, ASSIA, Jstor, Source, Google Scholar, Academia.edu, Researchgate, Google (from the UK) and Google (from Nepal). We will also search websites of organisations working in emergencies such as United Nations High Commissioner for Refugees (UNHCR), World Health Organisation (WHO), United Nations Children's Fund (UNICEF), Humanity and Inclusion (HI), CBM International, International Disability Alliance (IDA), Women's Refugee Commission (WRC), and National Federation of the Disabled Nepal (NFDN). We will approach our advisory committee and personal contacts in disabled persons organisations in the global south to help us locate additional relevant grey literature. Our advisory committee consists of representatives from the National Federation of Disabled Nepal (an umbrella organization of people with disabilities, Nepal Disabled Women Association, Parents Federation of Persons with Intellectual Disabilities, Prayatna NEPAL (working for Blind and Visually Impaired Women), Resource Center for Rehabilitation and Development Nepal (working for the promotion and protection of rights of children/persons with disabilities and as a resource center on disability), and National Deaf Federation Nepal.

Publication status, publication date and language will be subjected to limits, with searches restricted to papers published in English or Nepali between May 1st 2011 May 30th 2021. Google searches will be conducted from within Nepal and within the UK as location settings affect search results. For google searches, we will limit our search to the first 10 pages. While searching in researchgate and academia.edu and organisational websites lacking a good search function, we will limit our search using the search website function in google - site:[website] "[search term]" and limit out search to the first 10 pages. We will use a list of search terms related to youth, disability, humanitarian emergencies, low-and middle-income countries and COVID-19. Our search terms are presented in appendix 1. Four reviewers will search allocated databases (BR, DK, SW, and SP). Search results in Nepali will be reviewed by DK and SP.

Stage III: Study selection and eligibility criteria

We will apply inclusion and exclusion criteria. Given the sparsity of research, we will include literature where the age range of participants is unclear or crossed the age range specified (10-19) if the research focuses on children and young people with disabilities.

Inclusion criteria

- Literature which reports data from children and young people with disabilities between the ages of 10-19 years old inclusive

- Literature from low- and middle-income countries as classified by the World Bank <https://data.worldbank.org/country>
- Any study design but must report on empirical data
- Published between May 2011-May 2021
- Literature published in English and Nepali language

Exclusion criteria

- Literature published outside our language and date inclusion criteria.
- Literature not reporting on empirical data ie not based on observed and/or measured phenomena.
- Literature that reported on those who were disabled by or after the humanitarian disaster, event, or by COVID-19.

Literature will be manually uploaded in an excel file with columns identifying author, title, year of publication, and a hyperlink where possible. Where reviewers are doubtful of inclusion/exclusion, the literature will be uploaded and flagged for further review. Once searches are complete, BR will develop a final spreadsheet of the literature and manually remove duplicates.

Stage IV: Charting the data

Initially, five reviewers (BR, DK, SW, SP and JM) will extract data on the same five publications about publication year, literature type (grey or peer-reviewed), study population (age group and number of participants), methodology (qualitative, quantitative, or mixed methods), methods and sampling, study location (rural, urban or unclear), findings and recommendations into an excel spreadsheet. The publications will be chosen to represent a mix of literature types and focus areas ie some will be COVID-19 focused and others will be humanitarian focused. We will not assess 'quality' because we anticipate that it will be challenging to apply criteria to grey literature which may not report methods consistently.

We will conduct data extraction independently, and then discuss our charting to check for consistency and break down the 'findings' category further into thematic areas. Thereafter each reviewer will be allocated literature and they will independently extract data into the spreadsheet. Any uncertainties will be discussed in weekly team meetings. References will be uploaded in Zotero – an open access reference manager software.

Stage V: Collating, summarising and reporting results

Following data extraction, we will present results numerically and narratively. Numerical results will include on how many were grey versus peer-reviewed literature, how many reported research with children and young people with disabilities versus caregivers, how many were specific to COVID-19, and the methods used – participatory, phone, or in-person. Narrative results will include a description of findings and evidence gaps, and a description of the way that methods and tools were used.

Stage VI: Consultation

We will share preliminary findings from this review with our advisory group of disabled persons organisations (DPO) representatives through an online discussion to 1) understand how international findings resonate with the Nepal context 2) gain their input on the implications of the findings, and 3) obtain their input on recommendations for addressing gaps in the literature. We will also discuss to what extent we can act on our implications within planned project outputs. We will report on who participates in this discussion, and how they were selected. We will record the discussion (with consent) and integrate these discussions in the publication of the review.

Dissemination

We will disseminate our review through open access peer-reviewed publication and at a webinar where we will present the results of PARDAN. This webinar will be inclusive and will have translation between English and Nepali languages. We will produce a short report (in English and Nepali) which will be disseminated to participants of the study and through policy and DPO networks in Nepal. Our research will also be disseminated through websites and social media, and through the 'Disability under seige' research network co-ordinated by the University of Birmingham. This scoping review will inform the development of recommendations as part of the PARDAN and will be an important resource for those seeking to understand the experience of child and young people with disabilities in LMICs.

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Appendix 1 Search terms

Children with disabilities AND COVID-19 in Nepal
Children with disabilities AND disease outbreaks in Nepal
Children with disabilities AND humanitarian emergencies in Nepal
Children with disabilities AND natural disasters¹ in Nepal
Children with disabilities AND conflict in Nepal
Disabled children AND COVID-19 in Nepal
Disabled children AND disease outbreaks in Nepal
Disabled children AND humanitarian emergencies in Nepal
Disabled children AND natural disasters in Nepal
Disabled children AND conflict in Nepal

Children with disabilities AND COVID-19 in low- and middle-income countries
Children with disabilities AND disease outbreaks in low- and middle-income countries
Children with disabilities AND humanitarian emergencies in low- and middle-income countries
Children with disabilities AND natural disasters in low- and middle-income countries
Children with disabilities AND conflict in low- and middle-income countries
Disabled children AND COVID-19 in low- and middle-income countries
Disabled children AND disease outbreaks in low- and middle-income countries
Disabled children AND humanitarian emergencies in low- and middle-income countries
Disabled children AND natural disasters in low- and middle-income countries
Disabled children AND conflict in low- and middle-income countries

Children with disabilities AND COVID-19
Children with disabilities AND disease outbreaks
Children with disabilities AND humanitarian emergencies

Children with disabilities AND natural disasters
Children with disabilities AND conflict
Disabled children AND COVID-19
Disabled children AND disease outbreaks
Disabled children AND humanitarian emergencies
Disabled children AND natural disasters
Disabled children AND conflict

Youth with disabilities AND COVID-19 in Nepal
Youth with disabilities AND disease outbreaks in Nepal
Youth with disabilities AND humanitarian emergencies in Nepal
Youth with disabilities AND natural disasters in Nepal
Youth with disabilities AND conflict in Nepal
Disabled youth AND COVID-19 in Nepal
Disabled youth AND disease outbreaks in Nepal
Disabled youth AND humanitarian emergencies in Nepal
Disabled youth AND natural disasters in Nepal
Disabled youth AND conflict in Nepal

Teen* with disabilities AND COVID-19 in Nepal
Teen* with disabilities AND disease outbreaks in Nepal
Teen* with disabilities AND humanitarian emergencies in Nepal
Teen* with disabilities AND natural disasters in Nepal
Teen* with disabilities AND conflict in Nepal
Disabled teen* AND COVID-19 in Nepal
Disabled teen* AND disease outbreaks in Nepal
Disabled teen* AND humanitarian emergencies in Nepal
Disabled teen* AND natural disasters in Nepal
Disabled teen* AND conflict in Nepal

Youth with disabilities AND COVID-19 in low- and middle-income countries
Youth with disabilities AND disease outbreaks in low- and middle-income countries
Youth with disabilities AND humanitarian emergencies in low- and middle-income countries
Youth with disabilities AND natural disasters in low- and middle-income countries
Youth with disabilities AND conflict in low- and middle-income countries
Disabled youth AND COVID-19 in low- and middle-income countries
Disabled youth AND disease outbreaks in low- and middle-income countries
Disabled youth AND humanitarian emergencies in low- and middle-income countries
Disabled youth AND natural disasters in low- and middle-income countries
Disabled youth AND conflict in low- and middle-income countries

Teen* with disabilities AND COVID-19 in low- and middle-income countries
Teen* with disabilities AND disease outbreaks in low- and middle-income countries
Teen* with disabilities AND humanitarian emergencies in low- and middle-income countries

Teen* with disabilities AND natural disasters in low- and middle-income countries
Teen* with disabilities AND conflict in low- and middle-income countries
Disabled teen* AND COVID-19 in low- and middle-income countries
Disabled teen* AND disease outbreaks in low- and middle-income countries
Disabled teen* AND humanitarian emergencies in low- and middle-income countries
Disabled teen* AND natural disasters in low- and middle-income countries
Disabled teen* AND conflict in low- and middle-income countries

Youth with disabilities AND COVID-19
Youth with disabilities AND disease outbreaks
Youth with disabilities AND humanitarian emergencies
Youth with disabilities AND natural disasters
Youth with disabilities AND conflict
Disabled youth AND COVID-19
Disabled youth AND disease outbreaks
Disabled youth AND humanitarian emergencies
Disabled youth AND natural disasters
Disabled youth AND conflict

Teen* with disabilities AND COVID-19
Teen* with disabilities AND disease outbreaks
Teen* with disabilities AND humanitarian emergencies
Teen* with disabilities AND natural disasters
Teen* with disabilities AND conflict
Disabled teen* AND COVID-19
Disabled teen* AND disease outbreaks
Disabled teen* AND humanitarian emergencies
Disabled teen* AND natural disasters
Disabled teen* AND conflict