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HUMANITARIANISM AND COVID-19: STRUCTURAL DILEMMAS, FAULT LINES, AND NEW PERSPECTIVES

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The Health of People with Disabilities in Humanitarian Settings During the Covid-19 Pandemic*

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Abstract People with disabilities are at a higher risk of poor health outcomes and face barriers to accessing health services, which may be exacerbated in humanitarian settings and during the Covid-19 pandemic. This scoping review explores how best to protect the health of people with disabilities in humanitarian contexts during the Covid-19 response. Forty-eight articles across the peer-reviewed and grey literature were identified. Key challenges include a lack of accessibility of mainstream Covid-19 prevention and response measures, disruptions to routine care pathways for people with disabilities, and double discrimination based on disability and displaced status. Specific priority areas include continuity of basic and specialised services, prioritisation of women and children with disabilities, the need to adapt mainstream recommendations for the Covid-19 response to be disability- and humanitarian-setting inclusive, and strengthening data systems.

Keywords disability, Covid-19, pandemic, humanitarian setting, emergencies, inclusive health.

1 Background

An estimated 15 per cent of the global population has a disability. This percentage may be even higher amongst the world's 82.4 million forcibly displaced people (Women's Commission for Refugee Women and Children 2008; WHO and World Bank 2011; UNHCR 2021). People with disabilities include 'those with long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others' (UN 2006). Globally, people with disabilities and their families are at significant risk of discrimination, stigma, and violence, and face barriers to accessing health and social services, all of which may be exacerbated in humanitarian settings and during the ongoing Covid-19 pandemic.

The rights of people with disabilities to health is enshrined in Articles 25 and 26 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), which has been ratified by 182 states (*ibid.*). The right to health comprises equitable access to the same health services as the rest of the population, and, in the context of the current pandemic, includes health services for preventing and treating Covid-19, including vaccines, sanitation and hygiene measures, and access to personal protective equipment (PPE) (UN 2020; Kuper *et al.* 2020). People with disabilities may have additional health needs related to their disability, and so require access to specialist health services (Kuper and Heydt 2019; Shakespeare, Ndagire and Seketi 2021).

However, even before the pandemic, people with disabilities in humanitarian and non-humanitarian settings faced physical, informational, financial, and attitudinal barriers to accessing required health care, which often led to poorer levels of health, decreased functioning, and a reduction in social participation (Kuper and Heydt 2019; UN 2019). Specialised health and rehabilitation services are almost entirely absent in many humanitarian settings, including camps, and as such, treatable medical conditions can progress into significant impairments due to lack of proper medical attention (Mirza 2015). Disability is also not routinely considered when planning health services in humanitarian settings, leading to limited accessibility and appropriateness (*ibid.*; Hunt 2020).

Little is known about the health and health-care access of people with disabilities in humanitarian settings during the Covid-19 pandemic. Yet, existing evidence has highlighted that the health of people with disabilities in non-humanitarian settings has been disproportionately affected by the pandemic (Shakespeare, Ndagire and Seketi 2021; Shakespeare *et al.* 2021; Williamson *et al.* 2021). The health inequalities faced by people with disabilities may be further exacerbated when response planning and service delivery in the context of the pandemic are not inclusive or fail to consider the impact that decisions will have for people with disabilities (Perry *et al.* 2020; ACAPS-NPM Analysis Hub 2021).

The pandemic, and measures necessary for its containment, pose a particular threat and challenge in humanitarian settings. For example, containment measures such as mass 'stay-at-home' orders, social distancing, and quarantine are often difficult to implement in humanitarian settings such as camps (Hunt 2020). Displaced people living outside of camps may not be able to access health services for Covid-19 prevention and treatment if they do not have recognised legal status, or they may lack access to information on Covid-19 if it is not available in their own language.

People in humanitarian settings and people with disabilities, then, need special consideration within the Covid-19 response.

However, there is a lack of evidence exploring the intersection between the two groups. This article therefore seeks to review the available evidence and guidance on how to support the health of people with disabilities in humanitarian settings³ during the Covid-19 pandemic.

Section 2 describes the methods used in this evidence synthesis and Section 3, the results of our search. Section 4 discusses the key themes emerging from the review, with a focus on key challenges and lessons learned. We conclude, in Section 5, by noting the implications of our findings for research and practice.

2 Methods

We conducted a scoping review of the literature with a narrative synthesis. Non-systematic reviews of this kind are appropriate where there is a variety of evidence from different disciplines, and on a topic for which there have been few prior evidence syntheses (Greenhalgh, Thorne and Malterud 2019).

2.1 Search strategy

There are six types of information which are relevant to synthesising learning about how to support the health of people with disabilities in humanitarian settings during the Covid-19 pandemic. These include information about what works to improve health among the following groups:

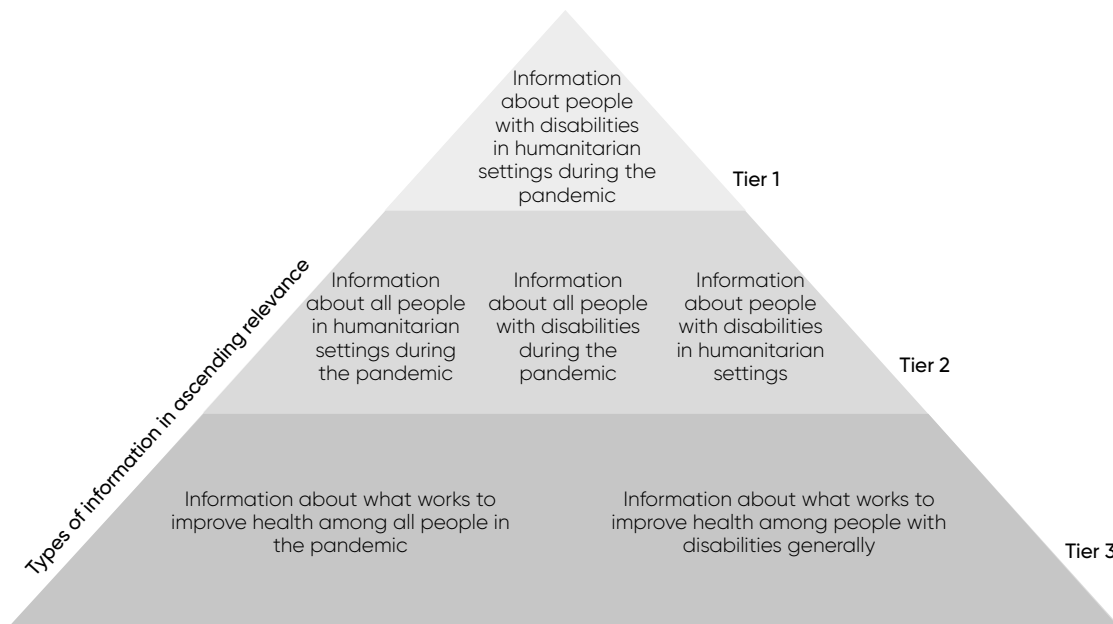
- 1 All people in humanitarian settings;
- 2 All people in the Covid-19 pandemic;
- 3 People with disabilities generally;
- 4 People with disabilities in humanitarian settings generally;
- 5 People with disabilities in the Covid-19 pandemic; and
- 6 People with disabilities in humanitarian settings in the context of the Covid-19 pandemic.

These different types of information, summarised in Figure 1, also exist across both grey literature and peer-reviewed publications.

To provide a broad overview of the literature, but not lose the specificity of the research question, our review focuses on the top two tiers of the pyramid in Figure 1 (the four types of information most relevant to our question).

The search was structured as follows. First, new evidence specific to the situation of people with disabilities in humanitarian settings during the Covid-19 pandemic (Tier 1 of Figure 1) was gathered through systematic searching of key academic databases (Africa-Wide Information, MEDLINE, Embase Classic+Embase, PsycINFO, CINAHL, ERIC, CENTRAL, Scopus). Preprint databases

Figure 1 Hierarchy of information relevant to the research question 'How to support the health of people with disabilities in humanitarian settings during the Covid-19 pandemic?'



Source: Authors' own.

medRxiv and OSF preprints were also searched, as was Google Scholar. Grey literature was searched using ReliefWeb, a database managed by the United Nations Office for the Coordination of Humanitarian Affairs. Terms related to 'disability', 'Covid-19', and 'humanitarian settings' were used. The search was restricted to 2020 to July 2021, given that the World Health Organization (WHO) declared the Covid-19 outbreak a global pandemic on 11 March 2020. Findings from this search were exported, abstracts screened, and included full texts reviewed for relevant content (see Section 2.2).

Second, given the expected lack of evidence from the first search, we sought to identify additional literature relevant, but not necessarily specific, to the health of people with disabilities in humanitarian settings during the Covid-19 pandemic – literature covering topics in the second tier in Figure 1. To do so, we drew on Disability Evidence Portal Briefs, which are rapid reviews (that were written or reviewed by Xanthe Hunt) that provide recommendations on supporting the health of people with disabilities during the Covid-19 pandemic and/or in humanitarian settings (Hunt 2020; Wilbur and Hunt 2020; Qureshi and Scherer 2020), and relevant grey literature and academic publications identified from the reference lists of studies included in the first search. These sources carried important information about supporting the health of people with disabilities in humanitarian settings and/or during past times of crisis. Drawing on these

sources is particularly important given the timescales for research and publication, and the need for urgent responses in the initial stages of the pandemic which would not have been possible based on current evidence alone.

No restrictions were placed on publication type, and editorials, grey literature, impact studies, and descriptive research were all eligible for inclusion.

2.2 Publication management and extraction

Included publications from both search strategies were critically reviewed, relevant information entered into an Excel spreadsheet, and the information organised according to its relevance to the specific research question (i.e. along the tiers in Figure 1). Extracted information included the following:

- Publication type (e.g. editorial, observational study, review);
- Type of health care covered (e.g. sexual and reproductive health, primary health care);
- Key challenges and barriers to health for people with disabilities in humanitarian settings and/or during the pandemic; and
- Strategies and guidance for supporting access to health for people with disabilities in humanitarian settings and/or during the pandemic.

In the findings discussed next, primacy is always given to information gathered from publications with the greatest specificity (Tier 1), and from peer-reviewed reviews.

3 Results and narrative synthesis

3.1 Results

Twelve publications were retrieved that were specific to the experience of people with disabilities in humanitarian settings during the Covid-19 pandemic (Tier 1 of Figure 1). All 12 publications were grey literature. A further 36 publications were identified covering topics in Tier 2 of the Figure 1 pyramid: 18 concerning the health of people with disabilities during the Covid-19 pandemic (outside of humanitarian settings), nine on the health of people with disabilities in humanitarian settings (not in the Covid-19 pandemic), and nine concerning the health of all people in humanitarian settings during the Covid-19 pandemic (not specifically people with disabilities). Included publications are listed in Annexe 1.

Several documents published by organisations working in humanitarian contexts (e.g. UN agencies, non-governmental organisations (NGOs)) recognised the increased risk faced by people with disabilities during the Covid-19 pandemic, including the potential for exclusion from needed routine health care

Table 1 Key findings and priorities for action

Domain	Challenges for people with disabilities in humanitarian settings	Priority actions
Covid-19-related health care		
Following preventative measures	<ul style="list-style-type: none"> ● Increased need for sanitation supplies (e.g. due to incontinence, reliance on others/surfaces to move around) ● Lower capacity to pay for increased need for sanitation supplies ● WASH⁴ facilities in humanitarian camps may be dangerous and inaccessible 	<ul style="list-style-type: none"> ● WASH infrastructure must be accessible and in safe locations ● Allocate hygiene products in line with specific needs ● Provide information in accessible formats and to carers
	<ul style="list-style-type: none"> ● Mask-wearing may be difficult for some (e.g. people using lip reading, people with cognitive impairments) ● Masks may not be available or affordable ● Social distancing may be impossible for people who require caregiving support for daily life activities ● Social distancing in densely populated humanitarian settings may be difficult 	<ul style="list-style-type: none"> ● Allow exemptions on mask-wearing for people with certain disabilities ● Provide free masks or materials for home-made masks ● Allow exemptions on social distancing for people who require caregiving support ● Provide caregivers with guidance on how to interact safely ● Alternatives to social distancing may be required (e.g. enhanced surveillance and testing) in camps
Information about Covid-19	<ul style="list-style-type: none"> ● Covid-19 information is not always in accessible formats ● Humanitarian camps or long-term care facilities may not be included in public health information campaigns 	<ul style="list-style-type: none"> ● Provide information in accessible formats, in the language(s) of the displaced population, in a range of different settings
	<ul style="list-style-type: none"> ● Public health information campaigns can be ableist and lead to discrimination against people with disabilities 	<ul style="list-style-type: none"> ● Include information about adaptations that people with disabilities can use to follow guidance ● Publicise and explain exemptions to following guidance ● Avoid stigmatising people for whom Covid-19 prevention behaviours are challenging
Access to health care for Covid-19	<ul style="list-style-type: none"> ● Greater risk of infection or severe disease from Covid-19 ● Financial, accessibility, attitudinal, and legal barriers accessing health care ● Stigma and discrimination can lead to the deprioritisation of care 	<ul style="list-style-type: none"> ● Barriers to health care must be addressed (e.g. improve accessibility of facilities, staff training) ● People with disabilities in humanitarian settings should not be excluded from treatment prioritisation based on their disability and/or refugee/displaced person status
	Access to vaccines	<ul style="list-style-type: none"> ● Limited provision of vaccines in humanitarian settings ● Financial, legal, accessibility, and attitudinal barriers may limit uptake

Other health needs and access to health care

	<ul style="list-style-type: none"> ● High pre-existing risk of violence due to disability and displaced status. Social distancing and isolation can increase risk of violence and limit options for escaping it ● Poor access to support services if non-inclusive or disrupted due to Covid-19 	<ul style="list-style-type: none"> ● Address drivers of violence (e.g. discrimination, social exclusion) ● Integrate intimate partner violence screening into routine services offered in humanitarian settings ● Promote the continuation of accessible services and supports for addressing and preventing violence during the pandemic
<p>Violence prevention and intervention</p>	<ul style="list-style-type: none"> ● Children with disabilities may be at elevated risk of exposure to violence, neglect, and exploitation (e.g. due to financial distress, loss of support networks) ● Children protection services not disability-inclusive and disrupted due to the pandemic 	<ul style="list-style-type: none"> ● Provide guidance and support to caregivers to keep their children safe ● Prioritise inclusive child protection efforts
	<ul style="list-style-type: none"> ● Beliefs that people with disabilities and displaced persons are carriers of the virus can lead to stigma, discrimination, and violence 	<ul style="list-style-type: none"> ● Conduct awareness campaigns dispelling misconceptions
<p>Access to needed health care</p>	<ul style="list-style-type: none"> ● Key health services have been disrupted ● People with higher health needs are more affected by disruptions ● Accessing health facilities and support services interrupted by restrictions ● Remote approaches may not be accessible or available 	<ul style="list-style-type: none"> ● Existing barriers (e.g. legal, financial, accessibility) to health care must be addressed ● Efforts to ensure the continuity of care (e.g. telemedicine) must be accessible and available in humanitarian settings ● Social protection should be available to people in need to offset the economic impacts of the pandemic
<p>Early identification and intervention with children with disabilities</p>	<ul style="list-style-type: none"> ● Pandemic-related restrictions reduce opportunities for disability detection 	<ul style="list-style-type: none"> ● Low-risk opportunities for engagement with caregivers of young children for detection and referral (e.g. assessments over phone/video; home-based visits with precautions)
<p>Mental health</p>	<ul style="list-style-type: none"> ● Social distancing, movement restrictions and lockdowns, as well as the negative social, health, and economic impacts of the pandemic, can lead to isolation and increased depression and anxiety ● Traditional mental health intervention modalities for humanitarian settings may not be possible under the restrictions of the pandemic 	<ul style="list-style-type: none"> ● Drivers of stress and isolation should be addressed ● Ensure programmes are inclusive of people with disabilities in humanitarian settings ● People with disabilities in humanitarian settings must be prioritised for psychosocial support programming ● Interventions must be adapted to the current situation by drawing on existing evidence and evaluating innovative approaches such as accessible videoconferencing

Source Authors' own.

(general and disability-specific) and health-care and preventative measures linked to Covid-19 (UN 2020; IASC 2020a, 2020b; Hall and Damon 2021; Live and Learn Environmental Education and CARE 2021; Syria Protection Cluster (Turkey) – Inclusion Technical Working Group 2021; United Nations Sustainable Development Group 2020; Humanity and Inclusion 2020). Still, little data were available – outside of a few small-scale, non-representative surveys conducted early in the pandemic by NGOs – documenting the experience of people with disabilities in humanitarian settings during the Covid-19 pandemic. Table 1 describes the available evidence and guidance on the health of people with disabilities in humanitarian contexts, and what is known from the broader evidence base on access to health care of people with disabilities in humanitarian settings or during the pandemic.

3.2 Key challenges affecting the health and health-care access of people with disabilities in humanitarian contexts during the Covid-19 pandemic

Table 1 summarises key challenges to supporting the health of people with disabilities in humanitarian settings during the pandemic, as well as priorities for action. Several cross-cutting issues were identified across challenges. First, people with disabilities in humanitarian settings face double discrimination on account of their disability and being a displaced person (Mirza 2015; Hossain *et al.* 2020). This discrimination may be heightened by the pandemic (UN 2020; Lokot and Avakyan 2020). For example, Turkish media have reported that refugees and asylum seekers are falsely blamed for spreading coronavirus and, as a consequence, face stigma and discrimination (Sevencan 2020). Similarly, people with disabilities can face discrimination if they are unable to follow certain guidelines (e.g. mask-wearing for people who lip read, or with intellectual impairments) (Humanity and Inclusion 2020; Qi and Hu 2020). Discrimination and violence not only have negative physical and mental health consequences but can prevent access to key health services (United Nations Sustainable Development Group 2020).

Second, people with disabilities in humanitarian settings faced systemic barriers to accessing essential services even before the pandemic (Schiariti 2020). For example, health and social services are often not disability-inclusive (e.g. lack of accessible communication, physically inaccessible and hard-to-reach facilities) (Kuper and Heydt 2019; Shakespeare, Bright and Kuper 2018). Within camp settings, needed services may be in limited supply, while displaced people living in communities may not be able to access available services due to their lack of legal status or the lack of communication/information in their preferred language (Hunt 2020). The pandemic has brought further challenges, as many health services were disrupted due to the strain on many health systems (Shakespeare, Ndagire and Seketi 2021; Shakespeare *et al.* 2021). Evidence from several settings indicates disruptions were particularly difficult for people with disabilities,

given their increased need for health services and products (e.g. rehabilitation, assistive devices, medication) for functioning and participation (UNRWA 2020; Human Rights Watch 2020).

Third, the pandemic is disrupting key referral pathways into much-needed care for people with disabilities in humanitarian settings (United Nations Sustainable Development Group 2020). For instance, routine sexual and reproductive health services are a critical entry point for women affected by violence, and when disrupted, opportunities for gender-based violence screening are missed (Lokot and Avakyan 2020). Similarly, closure of schools and other programmes for children may reduce opportunities for early identification of disability and disability-related services, as well as child protection mechanisms (Shakespeare *et al.* 2021; United Nations Sustainable Development Group 2020; Leonard Cheshire Working Group on Inclusive Education 2020).

Fourth, the pandemic is likely deepening pre-existing inequalities, which can drive negative health consequences. For example, the Covid-19 pandemic has caused financial strain for many people, but people with disabilities and in humanitarian settings already were more likely to be in poverty before the pandemic (Banks *et al.* 2020; Banks, Kuper and Polack 2017). Worsening economic status can then prevent people with disabilities in humanitarian settings from following preventative measures (e.g. affording sanitisation products) and accessing needed services for both Covid-19 and other health care.

Finally, recommendations for pandemic responses, including in humanitarian settings, may be unsuitable for people with disabilities (Humanity and Inclusion 2020; Qi and Hu 2020). For example, guidance may not consider specific challenges that people with disabilities in humanitarian settings may face in following prevention guidelines or accessing Covid-19 health care. Similarly, adaptations are not made to account for the varying needs of people with disabilities in humanitarian settings (e.g. some people with disabilities have the additional need for safe water/hygiene supplies due to both their impairment and Covid-19, but allocation of these supplies in humanitarian settings tends to be set at a standard amount for all).

4 Ways forward

Table 1 highlights strategies to support the health of people with disabilities in humanitarian settings during the Covid-19 pandemic. Specific priority areas include continuity of basic and specialised services, the prioritisation of women and children with disabilities, the need to adapt mainstream recommendations for Covid-19 responses to be disability- and humanitarian-setting inclusive, and strengthening data systems.

Continuity of basic and specialised services for people with disabilities in humanitarian settings is essential, as disruptions can

lead to worsening health and functioning (San Lau *et al.* 2020; Tran *et al.* for the Inter-Agency Working Group on Reproductive Health in Crises 2020). Continuity of mental health-care services is particularly important given the associations between the pandemic and increased stress (Qureshi and Scherer 2020; Nankervis and Chan 2021). Remote provision (e.g. through phone, video appointments) is increasingly used as a strategy to access key services during the pandemic (UN 2020; Hunt 2020; IASC 2020a). These strategies may improve access to health care for people with disabilities in humanitarian settings both during and beyond the pandemic, particularly for disability-related health care, which is often urban-based and in limited supply. Still, these remote alternatives must be available in accessible formats (e.g. sign language interpretation available, screen-reader compatible platforms) (UN 2020; IASC 2020a; United Nations Sustainable Development Group 2020). Further, complementary efforts are needed to promote access to needed technology for people with disabilities in humanitarian settings, as this group is likely to have poorer access due to higher levels of poverty (Banks *et al.* 2017).

Women and children with disabilities need specific consideration during the Covid-19 response in humanitarian settings, as isolation, reliance on distant WASH services, and isolation in the home with abusive family members can elevate vulnerability to gender-based violence and child abuse (Wilbur and Hunt 2020). WASH stations need to be close enough to where people live so as not to place women and children at risk of violence (*ibid.*). They must also be accessible to people with disabilities so that they can be used independently and hygienically (Kuper *et al.* 2020; Wilbur and Hunt 2020). Efforts must be made to ensure continuity in sexual and reproductive health services for women with disabilities and early identification and intervention for children with disabilities so that existing vulnerabilities are not exacerbated during the pandemic (Tran *et al.* for the Inter-Agency Working Group on Reproductive Health in Crises 2020; Tanabe *et al.* 2015). Further, as intimate partner violence rates may spike during lockdown, continuity of routine services for women (such as antenatal care) must be ensured to allow for ongoing intimate partner violence screening (Lokot and Avakyan 2020).

Mainstream recommendations for the containment of Covid-19 need to be adapted to be both disability-inclusive and appropriate for different humanitarian settings (including camps) (Hunt 2020; United Nations Sustainable Development Group 2020; Qi and Hu 2020). People with disabilities and their carers in humanitarian settings need to be supported to implement disease control measures such as social distancing and hygiene, through specific and accessible guidelines and material support (e.g. provision of additional soap, water, and other hygiene products based on need rather than on universal standards) (Shakespeare, Ndagire and Seketi 2021; Hall and Damon 2021;

Syria Protection Cluster (Turkey) – Inclusion Technical Working Group 2021). Given the challenges of social distancing, both due to the crowded nature of many humanitarian settings and the need for caregiving support for some people with disabilities, alternatives such as priority testing and access to PPE and vaccination for people with disabilities and their caregivers may be necessary and of benefit in humanitarian settings (IASC 2020a).

Additionally, organisations of persons with disabilities (OPDs) and people with disabilities from humanitarian settings must be consulted during all stages of planning and implementation to ensure that the resulting policies and programmes reflect the priorities and needs of people with disabilities in humanitarian settings during the pandemic (Hall and Damon 2021; Live and Learn Environmental Education and CARE 2021; Humanity and Inclusion 2020; Rotas and Cahapay 2021). OPDs and other networks can be leveraged to identify opportunities and resources to make the Covid-19 response more inclusive (Hunt *et al.* 2021).

Finally, to inform planning and programming, data systems in humanitarian settings must be strengthened to collect sex, age, and disability disaggregated data, including on differing rates of infection, access to key services (e.g. vaccination uptake), impacts on families, and violence exposure (ACAPS-NPM Analysis Hub 2021; Hall and Damon 2021; Humanity and Inclusion 2020). This review revealed the lack of primary data on the experience of people with disabilities in humanitarian settings, indicating a pressing need for further research. While the lack of data should not delay action, rigorous research can help to identify further priorities and strategies for tailoring responses.

5 Conclusion

People with disabilities in humanitarian settings face compounded challenges to protecting their health and accessing needed care during the Covid-19 pandemic due to the interaction of disability and living in a humanitarian setting. Most of the evidence from this scoping review was not specific to the experience of people with disabilities in humanitarian settings during the Covid-19 pandemic and was based on guidelines produced by NGOs and international NGOs (INGOs) rather than primary data. While helpful, further primary research is needed to better understand the experiences of people with disabilities in humanitarian settings during the Covid-19 pandemic, and their inclusion in response actions. Rights- and evidence-based approaches are needed to ensure that people with disabilities in humanitarian settings are not left behind in the pandemic response (Schiariti 2020; Battle 2015; Kluge *et al.* 2020). Dignity and respect for the rights of people with disabilities need to be the starting point from which all response actions must develop. Strategies for containing Covid-19 must not worsen inequalities and reinforce ableist assumptions (Rotarou *et al.* 2021).

Notes

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- 3 It is worth briefly noting that humanitarian emergencies are very diverse phenomena, and differences between them will influence the types of provisions which are needed to support the health of people with disabilities. However, the purpose of our review is to identify general guidance which can be applied to supporting inclusive responses to the pandemic.
- 4 WASH = water, sanitation, and hygiene.

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Annexe 1 Included literature

Reference	Types of information				Categories of publication			
	Health + People with disabilities + humanitarian settings + Covid-19 pandemic	Health + people with disabilities + Covid-19 pandemic	Health + people with disabilities + humanitarian settings	All people in humanitarian settings + Covid-19 pandemic	Impact evaluation	Descriptive study	Evidence synthesis	Editorial/commentary/guidance document/grey literature
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