

BMJ Open Are the rights of people with disabilities included in international guidance on WASH during the COVID-19 pandemic? Content analysis using EquiFrame

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ABSTRACT

Purpose People with disabilities are at increased risk from COVID-19. Access to water, sanitation and hygiene (WASH) services and facilities is a fundamental right for all, and is vital in stopping the transmission of COVID-19. However, people with disabilities often face difficulties accessing WASH. Various international organisations have published guidance and recommendations on WASH service provision during the COVID-19 pandemic, and this must include information of relevance to people with disabilities. This study aimed to investigate the inclusion of core concepts of rights for people with disabilities in guidance on WASH during the COVID-19 pandemic.

Method We used the EquiFrame content analysis tool to analyse the inclusion of 21 core concepts of rights for people with disabilities in international guidance documents on WASH during the pandemic. 29 documents were included from multilateral entities, international consortiums and non-governmental organisations. Key information from the included guidance documents was extracted for each of the 21 core concepts.

Results One-third of the WASH guidance did not include any reference to the rights of people with disabilities, and the majority of information was provided by just one guidance document. Most commonly referenced across all was access to WASH, including details on accessible infrastructure (eg, handwashing stations) and communication strategies. Information on many important rights and considerations, such as the affordability of services and caregiver support, was rarely included.

Conclusion Although some information is provided in international WASH guidance, this often has a narrow focus on access, rather than the full array of rights and considerations that are important for people with disabilities. International guidance should continue to be reviewed and updated to include further information of relevance to people with disabilities, informing a disability-inclusive approach to WASH during the remainder of the COVID-19 pandemic and future crises.

INTRODUCTION

Disability considerations during the COVID-19 pandemic

In December 2019, the world experienced the first outbreak of SARS-CoV-2, a highly

Strengths and limitations of this study

- We used a systematic content analysis framework and tool, applied by two independent reviewers to ensure consistent and rigorous assessment of the included water, sanitation and hygiene documentation.
- Our search strategy was not able to capture the breadth of information and guidance published during this pandemic and documentation may have been missed.
- EquiFrame is not typically used to analyse international guidance, as we have done, but we believe the framework to be a suitable method and adaptation is endorsed by the original development team.

infectious virus causing the disease COVID-19. In March 2020, the WHO declared the outbreak a global pandemic.¹

As of 10 April 2021, there have been over 135 million documented cases of COVID-19, and close to 3 million deaths.² This pandemic has impacted the world's population on a scale not seen for generations, and vulnerable and marginalised groups, including people with disabilities, are being disproportionately affected.³

People with disabilities may be at greater risk of morbidity and mortality from COVID-19, especially if they have underlying health concerns, such as diabetes, asthma or chronic pulmonary obstructive disease, common conditions in this population.⁴⁻⁶ The prevalence of disability also increases with age, and is substantially more common in older adults; estimates indicate that half of adults aged 60+ live with a disability.⁴ Older adults are at a higher risk of poor health outcomes from COVID-19, and older adults with disabilities are at increased risk.⁷ Despite increased health needs, people with disabilities face inequalities in healthcare access, and this

can exacerbate the risk of COVID-19.⁸ Analysis from the UK indicates that the risk of death is three times higher among people with disabilities compared with people without disabilities.⁹ Many in the UK have reported feeling abandoned and forgotten by the government, with concerns on accessible information, ongoing health and healthcare access (including specialist rehabilitation) and an increased reliance on family care.¹⁰

In addition to health concerns and mortality, geopolitical and social changes arising from COVID-19 may also increase the inequalities experienced by people with disabilities in other areas of life. This includes an increased risk of stigma and violence.^{11–13} In Ethiopia, young people with disabilities expressed fear of violence during the pandemic (from police clearing the streets for social distancing, and more active youth gangs), and experts reported increased instances of sexual assault among women and girls with disabilities.¹⁴ Barriers to education and employment may also be more present, particularly with countries experiencing widespread school closures and workplace redundancies.^{4 15}

As well as the impacts on people with disabilities themselves, many informal caregivers are facing escalating challenges, as a result of increased caregiver duties during periods of self-isolation and with support services working at reduced capacity. Many caregivers have reported increased levels of stress and mental health concerns, as a result.¹⁶

Water, sanitation and hygiene for people with disabilities during the pandemic

Protection measures against the transmission of COVID-19, such as social distancing, can be difficult for many people with disabilities, who may be reliant on assistance from caregivers; thus increasing the risk of contracting the disease.⁵ Water, sanitation and hygiene (WASH) is vital in interrupting the transmission of COVID-19, with regular hand washing, bathing and washing of clothes important hygiene behaviours. As well as the importance of WASH in relation to COVID-19 transmission, people with disabilities may also have additional WASH needs (incontinence, for example), as well as an additional reliance on assistive devices (such as handrails, wheelchairs and communication aids) or support from caregivers, who may not have any technical knowledge or training in WASH support.¹⁷ Caregivers in the UK and India, for example, have reported difficulties in helping their dependents with autism and dementia, respectively, understand the need for hand washing, surface cleaning and social distancing measures.^{18 19}

Access to WASH facilities is often a major challenge for people with disabilities, especially in low-income and middle-income countries. Barriers include inaccessible infrastructure; for instance, water pumps, handwashing stations and bathing facilities that are not accessible to people with different impairment types. Without access, the risk of contracting the disease increases.^{17 20} Furthermore, the COVID-19 response requires population-level hygiene behaviour change (such as washing hands with soap and

wearing masks), and guidance is often communicated via mass media. If communication strategies and materials are inaccessible (for instance, announcements made on television provided with no sign language interpretation or closed captioning), people with disabilities may miss critical messages. The changes to the physical and social environment in times of crises mean that these barriers to WASH are more pronounced, and people with disabilities are at risk of marginalisation during the COVID-19 pandemic.²¹

International guidance on the COVID-19 pandemic

Numerous calls to action and policy briefs have been published on WASH practice and provision during the COVID-19 pandemic, with a heavy focus on hygiene behaviours, such as hand washing. Various multilateral entities, non-governmental organisations and WASH networks, including the WHO, UNICEF and WaterAid, have released guidance and recommendations for international actors and stakeholders.²² Access to WASH is a fundamental human right for all, and guidance on WASH during this pandemic must include considerations for people with disabilities, covering areas of importance and possible challenge, so that programme implementers, service providers and community members are informed on needed support.^{23 24}

Aims and objectives

This study aims to assess the extent to which global guidance documents on WASH during the COVID-19 pandemic include information on the rights of people with disabilities to WASH services and facilities.

Objectives

- ▶ To examine the extent to which guidance documents on WASH during the COVID-19 pandemic incorporates the rights of people with disabilities
- ▶ To identify the rights of people with disabilities that are most commonly valued and neglected in guidance documents on WASH during the COVID-19 pandemic

METHODS

We conducted a content analysis of international guidance documents on WASH during COVID-19 to understand the representation of rights for people with disabilities.

Selection of global documentation

To source guidance documents, we searched:

1. Resource centres on COVID-19 and disability or WASH (details in online supplemental file 1).
2. Websites of influential multilateral and bilateral agencies, non-governmental organisations and networks/coalitions working in WASH or disability related sectors (online supplemental file 1).

Additional documentation was sourced through our networks.

Inclusion criteria

Guidance and good practice documents, technical notes, policy briefs, open letters and calls to action that provide

information on WASH during the COVID-19 pandemic to a global or regional (eg, West Africa) audience that were:

1. Published by bilateral or multilateral agencies, international citizenship organisations, stakeholder networks and compendiums.
2. Focused on WASH or WASH and disability, in relation to the COVID-19 pandemic.

Exclusion criteria

- ▶ Tweets, Facebook posts and personal opinion pieces.
- ▶ Internal documents, designed to inform stakeholders within the organisation itself, even if publicly available.
- ▶ Documents not in English.

Various guidance has been published on a disability-inclusive COVID-19 response; however, this is not specific to WASH and was not included.

In total, 29 documents were included, as detailed in online supplemental file 1. 13 (45%) of the documents come from multilateral agencies, 15 (52%) from coalitions (networks, compendiums, forums) and 1 (4%) from a non-governmental organisation (NGO).

Content analysis

The included documentation was analysed using EquiFrame, a content analysis tool designed to assess the inclusion of 21 core concepts of human rights in health policies. The 21 core concepts reflect human rights which must be considered in order to achieve universal health-care coverage, such as Access and Non-discrimination (table 1). Each core concept has a set of key questions and language to support consistent understanding and systematic scoring against its inclusion in policy content. For instance, the key question under the core concept of Access is: ‘Does the policy support vulnerable groups—physical, economic, and information access to health services?’

As encouraged in the EquiFrame manual, this tool has been adapted for use across sectors and across document types, including disability inclusive development good practice documentation.^{25 26} It has also been applied to the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), with 95% of the core concepts referenced across the convention, demonstrating the applicability of these concepts to disability inclusion.²⁷

The tool was originally designed to be used in assessments of health policies, somewhat different to the documentation included in this study. However, the EquiFrame development team encourage adapting use of the tool to suit varying needs and document types. We have used a version of this tool recently adapted to the WASH sector, in assessment of inclusion of the 21 concepts in national WASH policies and programmes in Cambodia, Bangladesh and Nepal, for people with disabilities.²⁸ For this adaptation, the key language and key questions were adapted to reflect the needs and rights of people with disabilities in the WASH sector, by mapping the core concepts against the ‘Human right

to water and sanitation’, adopted by the United Nations General Assembly in 2010.²³ The 21 core concepts, and the adapted key language and key questions of each are shown in table 1. As an example of adaptation, consider Core Concept 6 ‘Coordination of services’. Compared with the original, the adapted version includes additional information on the agencies that ought to coordinate a WASH response, including schools, health-services and households. These adaptations were reviewed and endorsed by the original EquiFrame development team.

Scoring and analysis

For each document, two independent reviewers (NS and JW) coded each reference to a core concept 1–4:

1. The concept was mentioned.
2. The concept was mentioned and explained.
3. Specific policy actions were identified to address the concept.
4. Intention to monitor the concept was expressed.

For example, a reference to the core concept of Participation, with a score of 3, may be: ‘People with disabilities should be consulted in the planning, implementation and monitoring of WASH programmes. Holding workshops and focus groups with people with disabilities in the planning phase will help drive forward programme content and structure.’

Discrepancies in scores were discussed and resolved between the reviewers. From the final scores, we calculated the following indices, as summarised across all included documents.

- ▶ Core Concept Reference: the proportion (%) of references to a core concept across all documents, providing insight into the relative inclusion of core concepts across all guidance documentation.
- ▶ Average Score: the average score across all guidance documents and all references to a concept, providing insight into the level of commitment to this right.

As well as these summary indices, we have compiled details on the key information emerging from the guidance documents, against each concept, and we have selected quotes to illustrate how core concepts have been included and referenced.

With our focus on the rights of people with disabilities to WASH, we did not score documents against the inclusion of all 12 vulnerable groups in the original EquiFrame, and focused on scoring the inclusion of core concepts as related to people with disabilities only.

RESULTS

Of the 29 documents included, 10 (35%) did not include reference to any core concept in relation to the rights of people with disabilities to WASH.

Table 2 details the proportion of references to the 21 core concepts across all included documentation, as well as the average score (from 1 to 4) across all references. Table 3 outlines the key information provided in the

**Table 1** 21 core concepts of EquiFrame, adapted for disability inclusion in the context of water, sanitation and hygiene (WASH)

No.	Core concept	Key question	Key language
1	Non-discrimination	Does the guidance support the rights of people with disabilities with equal opportunity in receiving WASH services?	People with disabilities are not directly or indirectly discriminated against within the WASH system
2	Individualised services	Does the guidance support the rights of people with disabilities with individually tailored WASH services to meet their needs, choices and impairments?	People with disabilities receive specific, appropriate and effective WASH services. This includes reasonable adjustments made/supported, when necessary
3	Entitlement	Does the guidance indicate entitlements for people with disabilities (eg, respite grant or reduced user fee), and how they may qualify for specific benefits relevant to them?	People with disabilities who have limited resources are entitled to some services free of charge or at a sliding scale tariff, especially if in unpaid work
4	Capability based services	Does the guidance recognise the capabilities of people with disabilities?	For instance, programmes including peer support, mentoring and group advocacy. People with disabilities are meaningfully represented in WASH committees and programmes may be implemented by Organisations of Persons with Disabilities (OPDs)
5	Participation	Does the guidance support the right of people with disabilities to participate in the decisions that affect their lives and enhance their empowerment?	People with disabilities can exercise choices and influence decisions affecting their life. Consultation may include planning, development, implementation and evaluation
6	Coordination of services	Does the guidance support assistance of people with disabilities in accessing services from within a single provider system (inter-agency) or more than one provider system (intra-agency) or more than one sector (inter-sectoral)?	People with disabilities know how services should interact where inter-agency, intra-agency and inter-sectoral collaboration is required. This includes coordination between health services, schools, households and public places, with regards to WASH. Additional coordination opportunities include the WASH sector with the private sector, civil society and rights groups
7	Protection from harm	Does the guidance outline that people with disabilities are to be protected from harm during their interaction with WASH and related services?	People with disabilities are protected from harm during their interaction with WASH services and health related systems, as well as from families and the community who may have negative attitudes about WASH for people with disabilities
8	Liberty	Does the guidance support the right of people with disabilities to be free from unwarranted physical or other confinement?	People with disabilities are protected from unwarranted physical or other confinement while in the custody of the service system/provider. This includes at home and a healthcare service.
9	Autonomy	Does the guidance support the right of people with disabilities to consent, refuse to consent, withdraw consent, or otherwise control or exercise choice over what happens to them?	People with disabilities can express 'independence' or 'self-determination'. For instance, persons with an intellectual disability will have recourse to an independent third party regarding issues of consent and choice.
10	Privacy	Does the guidance address the need for information regarding people with disabilities to be kept private and confidential?	Information regarding people with disabilities need not be shared among others
11	Integration	Does the guidance promote the use of mainstream services by people with disabilities?	People with disabilities are supported to use the WASH services that are provided for general population
12	Contribution	Does the guidance recognise that people with disabilities can be productive contributors to society?	People with disabilities make a meaningful contribution to society and the WASH sector
13	Family resource	Does the guidance recognise the value of the family members of people with disabilities in addressing WASH needs?	The document recognises the value of family members of people with disabilities as a resource for addressing WASH needs
14	Family support	Does the guidance recognise individual members of people with disabilities may have an impact on the family members requiring additional support from WASH services?	Caring for persons with disabilities may have mental health effects on other family members, such that these family members themselves require support
15	Cultural responsiveness	Does the guidance ensure that services respond to the beliefs, values, gender, interpersonal styles, attitudes, cultural, ethnic or linguistic, aspects of the person, as well as personal safety and dignity?	i) People with disabilities are consulted on the acceptability of the service provided ii) Hygiene facilities, goods and services are respectful of ethical principles and culturally appropriate, that is, respectful of the culture of people with disabilities
16	Accountability	Does the guidance specify to whom, and for what, services providers are accountable?	People with disabilities have access to internal and independent professional evaluation or procedural safeguard. Law/regulations provide mechanisms that ensure complaints are effectively heard and there are clear systems for people to lodge these complaints. Judicial bodies are available to resolve conflicts, for both public and private institutions

Continued

Table 1 Continued

No.	Core concept	Key question	Key language
17	Prevention	Does the guidance support people with disabilities in seeking primary, secondary and tertiary prevention of health conditions associated with WASH?	Includes WASH-related illnesses and details on how people with disabilities can seek primary, secondary and tertiary prevention of health conditions. For example, Trachoma, Soil-Transmitted Helminthes—intestinal worms, Lymphatic Filariasis, Leprosy, urinary tract infections
18	Capacity building	Does the guidance support the capacity building of health workers and of the system that they work in addressing WASH needs of people with disabilities?	Includes awareness raising among communities and families on disability and on the specific issues/barriers facing people with disabilities
19	Access	Does the guidance support people with disabilities—physical, economic and information access to WASH services?	People with disabilities have accessible and safe WASH services within, or in the immediate vicinity, of household, health and educational institutions, public institutions and workplace. All information must be understandable and in appropriate format
20	Quality	Does the guidance support quality services to people with disabilities through evidence-based and professionally skilled practice? Does the guidance promote innovation in WASH services for people with disabilities (eg, technology)?	People with disabilities are assured that services are based on best practice/evidence and support innovative strategies/technology
21	Efficiency	Does the guidance support efficiency by providing a structured way of matching WASH system resources with service demands in addressing WASH needs of people with disabilities?	WASH services are sustainable for people with disabilities. Services will be available at times of financial crisis and will ensure appropriate technology choices. Contracts with providers take into account operation and maintenance and funds from donors are sustainable

Table 2 Proportion of references to the 21 core concepts and average score across water, sanitation and hygiene (WASH) documentation

		WASH documents (n=349 references across 29 documents)	
		Total mentions	Average score
1	Non-discrimination	9%	2.3
2	Individualised services	13%	2.4
3	Entitlement	2%	2.8
4	Capability based services	4%	2.9
5	Participation	9%	2.6
6	Coordination of services	2%	3
7	Protection from harm	5%	2.7
8	Liberty	<1%	2
9	Autonomy	<1%	2.5
10	Privacy	0%	0
11	Integration	4%	2.5
12	Contribution	0%	0
13	Family resource	2%	2.8
14	Family support	1%	3
15	Cultural responsiveness	4%	2.6
16	Accountability	<1%	2
17	Prevention	4%	2.4
18	Capacity building	5%	2.9
19	Access	25%	2.4
20	Quality	7%	3
21	Efficiency	2%	2.2
Total		100%	

guidance, extracted from references to the core concepts scored 3 or 4; that is, those that provided specific actions.

Despite there being 29 included documents, over half (54%) of the references listed were extracted from a single document (Disability inclusion and COVID-19: Guidance for WASH delivery, Water for Women and CBM).

Across all documents, 19 (91%) of concepts were referenced at least once across all documents. *Access* (25%) was the concept most commonly referenced in the included documents, with information provided focused on themes of accessibility to WASH facilities and accessible communication strategies. *Individualised services* (13%) was next most common, with recommendations made towards the provision of additional WASH and hygiene products (eg, menstrual materials) to people with disabilities, and innovative methods to reach those that cannot leave their home, either due to self-isolation or severity of their impairment. Just two concepts were not mentioned at all across WASH-specific documents (*Privacy and Contribution*), although a number were referenced infrequently; $\leq 1\%$ of references (*Autonomy, Liberty, Family Support, Family Resource, Accountability*). In total, 71% of all references scored 3 or above, providing specific action points for programme and policy.

‘Accessible WASH facilities: Ensure that additional or temporary handwashing facilities installed within institutions are accessible to all users. Advocate for accessible WASH facilities to be retrofitted as part of any renovations being considered, for example during school closures.’ (Disability inclusion and COVID-19: Guidance for WASH delivery, Water for Women and CBM—scored Access)

Across all documents included in this study, 96% of references were made in relation to people with

**Table 3** Key information provided in water, sanitation and hygiene (WASH) documents, extracted from references to the core concepts scored 3 or 4

	Core concept	Key information provided
1.	Non-discrimination	<ul style="list-style-type: none"> Ensure hygiene promotion targets <i>everyone</i> in the community, regardless of gender, disability, and so on.
2.	Individualised services	<ul style="list-style-type: none"> Provide households with additional hygiene products and specific items (eg, menstrual hygiene materials and incontinence products) Households with a member with a disability may need more water to maintain good levels of hygiene and personal care Consider alternative ways of reaching people with disabilities who cannot leave their home (eg, contact their caregivers and family members)
3.	Entitlement	<ul style="list-style-type: none"> Subsidise utilities or provide cash transfers to vulnerable households
4.	Capability-based services	<ul style="list-style-type: none"> Consult with Organisations of People with Disabilities in programme and service provision Promote representation of people with disabilities on WASH committees
5.	Participation	<ul style="list-style-type: none"> Engage people with disabilities in programme planning, implementation, monitoring and evaluation Consult Organisations of People with Disabilities in WASH programme and service provision
6.	Coordination of services	<ul style="list-style-type: none"> Develop partnerships with local private actors, government and NGOs to secure WASH services and supplies for people with disabilities Civil society organisations can help governments identify people with disabilities and the appropriate support needed
7.	Protection from harm	<ul style="list-style-type: none"> Ensure privacy during personal care Address safety and risk of violence against people with disabilities when using WASH facilities, including a focus on gender-based violence
8.	Liberty	N/A
9.	Autonomy	<ul style="list-style-type: none"> Support must empower people with disabilities to be active participants in WASH decision-making
10.	Privacy	N/A
11.	Integration	<ul style="list-style-type: none"> Advocate for a more inclusive WASH response
12.	Contribution	N/A
13.	Family resource	<ul style="list-style-type: none"> Recognise the role of family members during this pandemic and support them to assist people with disabilities in accessing WASH
14.	Family support	<ul style="list-style-type: none"> Provide information and support to informal family caregivers on effective WASH behaviours in the home
15.	Cultural responsiveness	<ul style="list-style-type: none"> Respond to the diverse needs of people with different impairments; people with disabilities are not a homogenous group
16.	Accountability	<ul style="list-style-type: none"> Develop safe and responsive and responsive feedback/complaints mechanisms
17.	Prevention	<ul style="list-style-type: none"> Assistive devices should be cleaned regularly to prevent COVID-19 transmission Ensure continued care of pre-existing conditions by health services and provide services to prevent of other infections (eg, immunisation services, psychosocial support, nutrition)
18.	Capacity building	<ul style="list-style-type: none"> Provide training and guidance to households on how to support people with disabilities in using WASH facilities and adopting hygiene behaviours Promote disability awareness among staff in healthcare and WASH services, including appropriate communication
19.	Access	<ul style="list-style-type: none"> Provide accessible WASH facilities (eg, handwashing and bathing) Communication strategies must be adapted and accessible to people with varying impairments Maintain accessibility of WASH facilities across schools, healthcare, community settings, and so on. Where appropriate, use innovative technology to increase WASH access, but ensure this is accessible
20.	Quality	<ul style="list-style-type: none"> Conduct rapid reviews of WASH barriers and challenges faced by people with disabilities and their caregivers Conduct accessibility audits with people who have a disability Be evidence driven and evaluate effectiveness and acceptability of initiatives for people with disabilities Adapt WASH assessment and monitoring tools to collect information on the needs of people with disabilities and caregivers
21.	Efficiency	<ul style="list-style-type: none"> Ensure budget allocation for disability training, programme and policy activities in WASH activities Advocate with governments for disability-inclusive WASH to be included in national policies

NGO, non-governmental organisation.

disabilities as a broad group. 2% specifically mention adults and children with disabilities as individual groups, 1% focused on adults with disabilities only, and 1% on children with disabilities.

DISCUSSION

This study aimed to examine the communication of core concepts of human rights for people with disabilities in international guidance on WASH during the COVID-19 pandemic.

Despite widespread calls for a disability inclusive COVID-19 response, one-third of the COVID-19 WASH guidance documents reviewed did not refer to any core concept in relation to the rights and needs of people with disabilities.³ And as noted, the majority of information was extracted from a single guidance document from Water for Women and CBM. This is unacceptable given the rights of people with disabilities to WASH, the central importance of WASH in preventing transmission of COVID-19, and the additional risk of severe outcomes among this population.

When information is included, *Access* for people with disabilities is the major focus of the guidance documentation. *Access* has been a priority in disability inclusion advocacy over the past decade, and it is the most commonly referenced concept in the UNCRPD.^{27 29} Promoting access is vital for a disability inclusive WASH response, but guidance must also address aspects that contribute to this, whether that be the affordability of services or capacity building for service providers, who may need training to adapt and deliver accessible WASH facilities. Entitlement (and the affordability of services), for example, makes up just 2% of total references, despite people with disabilities being typically poorer than people without disabilities, and those who are poorer tending to have worse WASH access.^{30 31} COVID-19 has reduced employment opportunities and put strain on household finances, which may create further barriers to WASH services and may make it more difficult to buy necessary hygiene products, such as soap, menstrual materials and incontinence products. This is an example of an important consideration not reflected in international guidance.

The included guidance documentation makes relatively common reference to *Participation*, and the inclusion of people with disabilities and organisations of persons with disabilities (OPDs) in the planning and implementation of WASH initiatives. Too often people with disabilities are seen as passive beneficiaries of support initiatives, and it is encouraging to see guidance advocate for their inclusion as active and valued members of the planning cycle.²⁹ Guidance must continue to outline actions that apply to the guiding principle 'Nothing About Us, Without Us', both during this pandemic and future crises.³²

Very few references are made to *Family Resource* in international guidance, despite policies on self-isolation, social distancing and shielding resulting in essential family caregiving responsibilities during this pandemic. Family

members need information on how best to support someone to carry out effective hygiene behaviours (preventing transmission of COVID-19 and maintaining health), that can continue with minimal involvement from health and social care service providers and staff. There is also very little mention of *Family Support*, despite increased caregiving duties for family members (especially women), who may feel stressed or overwhelmed by caregiving duties.³³ There needs to be recognition of the additional WASH-related tasks carried out by family caregivers, so readers of international guidance, whether it be government or local community providers, can understand and address the issue.

Although referenced at points, *Protection from Harm* is typically neglected across the guidance, despite a growing body of evidence on violence experienced by people with disabilities when accessing WASH, and evidence that people with disabilities are vulnerable to, and indeed scared of violence during the pandemic.^{11 13 14 34} Safety and security across all aspects of life is a fundamental human right in the Sustainable Development Goals and the UNCRPD, and with particular risks associated with accessing and using WASH facilities, it is an area that requires further focus in international guidance during this pandemic. Examples of good practice to recommend in guidance include the practitioner's toolkit on safe and accessible WASH services, developed by the Sanitation and Hygiene Applied Research for Equity (SHARE) consortium.³⁵

Many of the gaps in the included guidance are consistent with barriers to WASH experience by people with disabilities. For example, information on family care and support is scarce, despite evidence from numerous settings (such as Malawi and Vanuatu) demonstrating the reliance of many people with disabilities on informal caregivers when accessing WASH, and a major barrier to that access being the limited knowledge and competence on WASH practices among carers.^{17 36} Rather than these barriers being addressed in guidance, as needed, they are often ignored, further entrenching these barriers for people with disabilities. These barriers are well known; the World Report on Disability and the UNCRPD outline these explicitly, and to see some of these reflected as gaps in information is concerning, especially when coming from multilateral organisations, that governments and service providers often look to for guidance.^{4 24} As seen in the UK, people with disabilities feel that the government have forgotten them in the COVID-19 response, and limited information on disability-inclusive WASH from multilateral organisations will further exacerbate this exclusion.¹⁰

In general, the key information emerging from the core concept references (table 3) are relevant at all times, not just during this COVID-19 pandemic. Very little of the information provided in guidance documentation is specific to the COVID-19 pandemic. Calls to conduct accessibility audits of WASH facilities or to promote disability inclusive WASH in healthcare services are not

unique to this situation. The majority of guidance should be being implemented anyway, in line with the Sustainable Development Goals' aim of 'leave no one behind' and the rights outlined in the UNCRPD.^{24 37} COVID-19 exacerbates challenges and barriers already in existence, and principles applicable in regular times are certainly important to reiterate during the pandemic, but there is need for additional guidance, specific to this situation. COVID-19 also presents an opportunity for learning on disability-inclusive WASH, and experiences on innovative approaches can be carried forward into future mainstreaming activities.

Finally, it is interesting to observe the near complete focus of references to people with disabilities as a general group, with very few instances of specific information on child health and WASH needs. Children are an important group to consider in the WASH sector, with each element crucial for child survival, growth and development.³⁸ Although evidence indicates that children are less likely to contract COVID-19 or suffer severe illness,³⁹ there still remains a need to provide targeted guidance for this group. Important issues to consider include WASH practices in schools, the dependency on family caregivers and specific hygiene issues (eg, menstrual health and hygiene in adolescent girls). With older adults most likely to have a disability, and with older populations at greatest risk of COVID-19, it is important that future guidance also include specific information for this group (just 1% of references in the included documents focused solely on the rights and needs of adults with disabilities). Older people are often the most marginalised in communities and are some of the hardest to reach groups.⁴⁰ Supporting older people with disabilities requires individualised approaches, and this should be reflected with information in international guidance.

The analysis in this study has demonstrated the commitment of international guidance documents to core concepts of human rights for people with disabilities, with regards to WASH during the COVID-19 pandemic. That just one guidance document provides the majority of information on a disability-inclusive response demonstrates how little regard has been paid to people with disabilities during the COVID-19 pandemic.

Future research is needed across multiple settings to identify how this guidance has been adopted by national and local actors. This research must involve and support people with disabilities to discuss their experiences of WASH support during the pandemic, to enable mapping of guidance to practice. This includes investigation into the different experiences of women and men with disabilities. Including people with disabilities in future guideline development will ensure that the areas of importance to people with disabilities are recognised during any local, national or global crisis.

Recommendations on an inclusive COVID-19 WASH response can be found via the COVID-19 Hygiene Hub.⁴¹

This consortium have developed a 14-step evidence brief on how best to ensure an inclusive response, both during this and future crises. Guidance includes information on consultation with OPDs, providing accessible information, and cleaning assistive products. This guidance advocates meaningful inclusion, rather than shallow 'lip-service', and endeavours to have people with disabilities at the forefront of the decision-making process, to ensure a response that best meets their needs. To compliment this guidance, the Hygiene Hub have developed a 'COVID-19 Inclusive WASH Checklist', with which organisations can self-assess their response and areas for improvement.⁴²

With us now over a year into the pandemic, we must acknowledge that many disability-inclusive efforts have fallen short, and the findings of this analysis come too late for a time-sensitive response. That said, it is important that guidance be updated to address the gaps identified, as the pandemic is far from over, especially in countries seeing slow vaccine distribution. It is also important that these findings stimulate improved WASH guidance during any future crises.

Limitations

Our search strategy was not able to capture the incredible breadth of information and guidance being provided during this pandemic, with information from online webinars, and other such dissemination methods, not being captured. Given a global shift to online learning and working during the pandemic, there is likely a great amount of information through these means that has not been analysed.

In addition, the list of searched organisations is not exhaustive, especially for condition specific organisations. The list was discussed with the teams at WaterAid and the International Centre for Evidence in Disability to ensure that the key actors in the WASH and disability sectors were included, but there may be omissions.

EquiFrame is typically used to assess the inclusion of rights in national policies, rather than international guidance, but we believe that the framework presents a useful method to assess the inclusion of rights for people with disabilities in relation to WASH during the COVID-19 pandemic, given their overarching applicability to health for this group.

In interpretation of the data, it is important to acknowledge that many of the core concepts may have been mentioned in the included documents, without a specific focus for people with disabilities. Topics such as *Family Support* may well have been captured more broadly, under general, all-encompassing language, that applies to the entire population. Although these concepts should ideally be covered for people with disabilities specifically, there may be relevant information that is useful for governments and services providers in the international guidance documents, that has not been captured in this study.

CONCLUSION

International guidance on disability inclusive WASH during the COVID-19 pandemic has focused largely on access to WASH services and facilities. With a myriad of other important considerations, such as caregiver support and affordability of services, it is important that guidance continue to be revised and updated to best support people with disabilities, both during the COVID-19 pandemic and during future crises. It must also be recognised that a disability-inclusive response to WASH is needed at all times, not just in times of emergency.

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REFERENCES

- Cucinotta D, Vanelli M. Who Declares COVID-19 a pandemic. *Acta Biomed* 2020;91:157–60.
- Johns Hopkins University and Medicine. Coronavirus resource center. Available: <https://coronavirus.jhu.edu/map.html>
- . Policy brief: a Disability-Inclusive response to COVID-19. New York, United Nations; 2020.
- . World report on disability. Geneva World Health Organization; 2011.
- Armitage R, Nellums LB. The COVID-19 response must be disability inclusive. *Lancet Public Health* 2020;5:e257.
- World Health organization. *Disability and health* <https://www.who.int/news-room/fact-sheets/detail/disability-and-health>
- Chatterji S, Byles J, Cutler D, *et al*. Health, functioning, and disability in older adults--present status and future implications. *Lancet* 2015;385:563–75.
- Kuper H, Heydt P. The missing billion: access to health services for 1 billion people with disabilities. *LSHTM* 2019.
- Office for National Statistics. *Updated estimates of coronavirus (COVID-19) related deaths by disability status*. England: ONS, 2021.
- Shakespeare T, Watson N, Brunner R. Disabled people in Britain and the impact of the COVID-19 pandemic. *Preprints* 2021 <https://www.preprints.org/manuscript/202101.0563/v1>
- Hughes K, Bellis MA, Jones L, *et al*. Prevalence and risk of violence against adults with disabilities: a systematic review and meta-analysis of observational studies. *Lancet* 2012;379:1621–9.
- Campbell AM. An increasing risk of family violence during the Covid-19 pandemic: strengthening community collaborations to save lives. *Forensic Science International: Reports* 2020;2:100089.
- Lund EM. Interpersonal violence against people with disabilities: additional concerns and considerations in the COVID-19 pandemic. *Rehabil Psychol* 2020;65:199–205.
- Emirie G, Iyasu A, Gezahegne K. Experiences of vulnerable urban youth under covid-19: the case of youth with disabilities. *London: Gender and Adolescence: Global Evidence* 2020 <https://www.gage.odi.org/publication/experiences-of-vulnerable-urban-youth-under-covid-19-the-case-of-youth-with-disabilities/>
- Mactaggart I, Banks LM, Kuper H, *et al*. Livelihood opportunities amongst adults with and without disabilities in Cameroon and India: a case control study. *PLoS One* 2018;13:e0194105.
- Park SS. Caregivers' Mental Health and Somatic Symptoms During COVID-19. *J Gerontology: Series B* 2021;76:e235–40.
- White S, Kuper H, Itimu-Phiri A, *et al*. A qualitative study of barriers to accessing water, sanitation and hygiene for disabled people in Malawi. *PLoS One* 2016;11:e0155043.
- Vaitheswaran S, Lakshminarayanan M, Ramanujam V, *et al*. Experiences and needs of caregivers of persons with dementia in India during the COVID-19 Pandemic-A qualitative study. *Am J Geriatr Psychiatry* 2020;28:1185–94.
- Pavlopoulou G, Wood R, Papadopoulos C. *Impact of Covid-19 on the experiences of parents and family carers of autistic children and young people in the UK*. London: UCL Institute of Education, 2020.
- Groce N, Bailey N, Lang R, *et al*. Water and sanitation issues for persons with disabilities in low- and middle-income countries: a literature review and discussion of implications for global health and international development. *J Water Health* 2011;9:617–27.
- Richard D, Kiani S. *Rapid review of disability and older age inclusion in humanitarian wash interventions*, 2019. <https://www.alnap.org/help-library/rapid-review-of-disability-and-older-age-inclusion-in-wash>
- Sanitation and water for all. COVID-19 and wash. Available: <https://sanitationandwaterforall.org/about/about-us/water-sanitation-hygiene/covid-19-and-wash>
- General assembly resolution 64/292, the human right to water and sanitation, A/RES/64/292. *United Nations General Assembly* 2010.
- Office of the United nations high commissioner for human rights. *Convention on the Rights of Persons with Disabilities* 2008 https://www.ohchr.org/Documents/Publications/AdvocacyTool_en.pdf
- Henderson C, Mannan H, Power J. Disability inclusive development good practices: level of commitment to core concepts of human rights. *DCID* 2017;28:32.
- MacLachlan M, Amin M, Mannan H, *et al*. Inclusion and human rights in health policies: comparative and benchmarking analysis of 51 policies from Malawi, Sudan, South Africa and Namibia. *PLoS One* 2012;7:e35864.
- Mannan H, MacLachlan M, McVeigh J. Core concepts of human rights and inclusion of vulnerable groups in the United nations convention on the rights of persons with disabilities. *Alter* 2012;6:159–77.
- Scherer N, Mactaggart I, Huggett C, *et al*. The inclusion of rights of people with disabilities and women and girls in water, sanitation, and hygiene policy documents and programs of Bangladesh and Cambodia: content analysis using EquiFrame. *Int J Environ Res Public Health* 2021;18. doi:10.3390/ijerph18105087. [Epub ahead of print: 11 05 2021].
- Enfield S. K4D Helpdesk report. Brighton, UK Institute of Development Studies; 2018, Mainstreaming disability and making WASH programmes inclusive.



- 30 Banks LM, Kuper H, Polack S. Poverty and disability in low- and middle-income countries: a systematic review. *PLoS One* 2017;12:e0189996.
- 31 McKibbin WJ, Fernando R. The Global Macroeconomic Impacts of COVID-19: Seven Scenarios. In: *CAMA Working Paper No19/2020. 2020; Available at SSRN*. <https://ssrn.com/abstract=3547729> or <http://dx.doi.org/10.2139/ssrn.3547729>
- 32 Charlton J. *Nothing about us without us: disability oppression and empowerment*. Berkley, CA: University of California Press, 1998.
- 33 Sharma N, Chakrabarti S, Grover S. Gender differences in caregiving among family - caregivers of people with mental illnesses. *World J Psychiatry* 2016;6:7–17.
- 34 Sommer M, Ferron S, Cavill S, *et al*. Violence, gender and wash: spurring action on a complex, under-documented and sensitive topic. *Environ Urban* 2015;27:105–16.
- 35 SHARE. *A practitioner's toolkit: Making water, sanitation and hygiene safer through improved programming and services*. <https://violence-wash.lboro.ac.uk/>
- 36 Mactaggart I, Baker S, Bambery L. Water, women and disability: using mixed-methods to support inclusive wash programme design in Vanuatu. *The Lancet Regional Health – Western Pacific* 2021;8 [https://www.thelancet.com/journals/lanwpc/article/PIIS2666-6065\(21\)00018-3/fulltext](https://www.thelancet.com/journals/lanwpc/article/PIIS2666-6065(21)00018-3/fulltext)
- 37 Nations U. *Transforming our world: the 2030 agenda for sustainable development*. Geneva: United Nations General Assembly, 2015.
- 38 Esteves Mills J, Cumming O. *The impact of water, sanitation and hygiene on key health and social outcomes: review of evidence*, 2017. https://www.lshtm.ac.uk/sites/default/files/2017-07/WASHEvidencePaper_HighRes_01.23.17_0.pdf
- 39 Ludvigsson JF. Systematic review of COVID-19 in children shows milder cases and a better prognosis than adults. *Acta Paediatr* 2020;109:1088–95.
- 40 Cavill S, Roose S, Stephen C. *Chapter 15 putting the hardest to reach at the heart of the sustainable development goals*, 2016: 245–66. <https://sanitationlearninghub.org/resource/putting-the-hardest-to-reach-at-the-heart-of-the-sustainable-development-goals/>
- 41 COVID-19 Hygiene Hub. How can we ensure people with disabilities, older adults, older adults with disabilities and their caregivers are included in all COVID-19 hygiene promotion programmes? 2020 Available from. Available: <https://resources.hygienehub.info/en/articles/4098118-how-can-we-ensure-people-with-disabilities-older-adults-older-adults-with-disabilities-and-their-caregivers-are-included-in-all-covid-19-hygiene-promotion-programmes2020>
- 42 COVID-19 Hygiene Hub. How can organisations assess whether COVID-19 response programmes are inclusive? 2020. Available: <https://resources.hygienehub.info/en/articles/4637812-how-can-organisations-assess-whether-covid-19-response-programmes-are-inclusive2020>