



## Briefing note



# Are the rights of people with disabilities included in international guidance on WASH during the COVID-19 pandemic?

Analysis of WASH and COVID-19 international guidance and the extent to which it captures the rights and needs of people with disabilities, using the EquiFrame tool.

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# Introduction



People with disabilities are at increased risk of dying from COVID-19, especially if they have pre-existing health conditions (1-3). In the UK, death rates of people with learning disabilities were six times higher than for the general population in 2020 (4).

Good water, sanitation and hygiene (WASH) and social distancing practices are critical to reduce the transmission of COVID-19.

Everyone has the right to WASH services and facilities, but people with disabilities often face difficulties with access. These challenges include barriers in the physical environment (such as inaccessible facilities), social (not having a voice in decision-making) and institutional (government-led COVID plans fail to make efforts to reach them). For example, information in hygiene campaigns may be inaccessible for people with visual, hearing or cognitive impairments. Furthermore, people with disabilities may be reliant on caregivers for daily

activities, including handwashing and bathing, making social distancing measures difficult and further increasing transmission risk.

Throughout the COVID-19 pandemic, international organisations have developed guidance and recommendations on WASH solutions (5). There has been a strong focus improving hygiene behaviours, such as handwashing. As people with disabilities are at increased risk from COVID-19, these guidance materials must include information of relevance and be accessible to people with disabilities and their caregivers.

## Box 1. Defining disability<sup>7</sup>

Persons with disabilities are: '...those who have 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.'

# About the study



This study aimed to assess how global guidance documents on WASH during the COVID-19 pandemic included information on the rights of people with disabilities to WASH services and facilities. The study has two objectives:

1. To examine the extent to which guidance documents on WASH during the COVID-19 pandemic incorporate the rights of people with disabilities
2. 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

The researchers conducted a content analysis of 29 international guidance documents on WASH during COVID-19. These documents came from multilateral entities, international consortiums and non-governmental organisations. The study did not look at social media, internal documents or documents not in English.

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. Key information from the guidance documents was extracted for each of the 21 Core concepts. This briefing note shares a summary of what the researchers found.

## What is the EquiFrame?

EquiFrame is a tool developed to assess the inclusion of Core concepts of human rights in health policies for groups that may be vulnerable (6). Each 'core concept' have a set of key language and questions. By using these key questions, policies can be scored against human rights criteria. For example, EquiFrame has been applied to the United Nations Convention on the Rights of Persons with Disabilities (UNCPRD), with 95% of the Core concepts included in the Convention (7). This demonstrates the applicability of these concepts when assessing documents in their inclusion of the rights of people with disabilities. For this study, the research team adapted the tool to focus on disability, WASH and COVID-19. Here are two examples of Core concepts:

| EquiFrame concept         | Key question                                                                                                                                           | Key language                                                                                                                                                              |
|---------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Non-Discrimination</b> | 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                                                                      |
| <b>Participation</b>      | 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 |

See Annex 1 for the full table of EquiFrame's 21 Core concepts and how they have been adapted for disability inclusion in the context of WASH and COVID-19.

For the remainder of the paper, we will use the term 'Core concepts'. We have selected five Core concepts (three well represented and two missing) to explore and summarise our findings from the 29 documents.

### Box 2. What is a 'core concept'?

In this study, a 'core concept' is a term from the Equiframe Tool. A core concept refers a key human right for people with disabilities. Each core concept is defined by a set of key questions and language. There are 21 Core concepts in total.

### Box 3. Defining the 5 Core Concepts most and least valued in documents reviewed

#### Most valued:

1. **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 institution, public institutions and workplace. All information must be understandable and in appropriate format.
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. **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.

#### Least valued:

4. **Entitlement:** Does the guidance indicate entitlements for people with disabilities (e.g. 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
5. **Family resource:** Does the guidance recognize the value of the family members of people with disabilities in addressing WASH needs? The document recognizes the value of family members of people with disabilities as a resource for addressing WASH needs.

## Exploring the Findings

One third of the WASH and COVID-19 guidance did not include information of relevance to any core concept in relation to the rights of people with disabilities. Two-thirds of the 29 documents made reference to at least one core concept. This is concerning as WASH is critical to prevention and mitigation of COVID-19 transmission. If guidance on WASH and COVID-19 does not specifically include people with disabilities, they risk being left out of responses.

### Valued concepts:

Information was most commonly provided with regards to the concept of *Access*. Guidance materials focused on the need for accessible WASH infrastructure and accessible communication strategies.

**“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*))

Guidance also commonly provided information of relevance to *Individualised services* for people with disabilities. Guidance materials reviewed made recommendations on the need for increased provision of WASH and hygiene products (e.g. menstrual hygiene materials) for people with disabilities. Some guidance materials incorporated innovative methods to reach people who were unable to leave their home, either due to their impairment or due to COVID-19 self-isolation requirements; this included better online engagement or coordination with caregivers. People with disabilities have historically found themselves excluded from WASH services and facilities, and it is positive to see *Access* and *Individualised*

services the key focus, with accessible WASH vital in preventing COVID-19.

In addition, guidance also promoted the concept of *Participation*. International WASH and COVID-19 guidance made reference to planning and implementation of WASH initiatives needing to include people with disabilities and Organisations of Persons with Disabilities. That information on *Participation* was commonly included in international guidance is encouraging. This upholds the 'Nothing About Us, Without Us' movement of disability inclusion in the COVID-19 pandemic, and aims to ensure people with disabilities actively take part in planning and other processes as valued partners, rather than passive beneficiaries.

However, despite these gains, the study found critical gaps in international guidance failing to address other Core concepts of human rights.

### Neglected concepts:

Many important Core concepts of human rights were rarely included or were found missing from the guidance documents.

Affordability of services, which is the WASH human right principle related to the core concept of *Entitlement*, was barely captured in the guidance materials. People with disabilities often experience greater poverty than those without disabilities, as they find it more difficult to gain employment and have less livelihood opportunities, a particularly concerning issue as we consider the economic impact of the pandemic. Unfortunately, guidance reviewed as part of this study fails to address this cost barrier to WASH services and facilities, despite a focus on other areas related to Access.

Information on caregiver support and the concept of *Family Resource* were also largely missing from COVID-19 and WASH guidance.



Many strategies to protect against COVID-19, such as social distancing, self-isolation and shielding, rely on support from family members and other caregivers, especially in contexts where regular support services have stopped, and individuals have seen primary care revert back to the family. People with disabilities are more likely to die from COVID-19, and family caregivers must be provided information on how to support a person with a disability to maintain effective hygiene behaviours and protect against infection, especially if they have limited experience of care and WASH strategies.

The review also found that information was provided in relation to people with disabilities as a broad group, without age-specific guidance. Very few guidance mentioned the rights of children with disabilities, as distinct from adults, despite their unique WASH needs.

Furthermore the review found that most guidance was relevant at all times to ensure people with disabilities access WASH services. Very little guidance was specific to the COVID-19 pandemic. While it is good practice to ensure the rights of people with disabilities are always included in WASH interventions, guidance during COVID-19 must be specific to this crisis.

# What do these findings mean for WASH and COVID-19 guidance?

Although information of relevance to people with disabilities is provided in international WASH guidance, often there is a narrow focus on Access, rather than the full array of rights and considerations that are important for this group during a global pandemic. The neglected concepts are an example of how international guidance is failing to consider important human rights of people with disabilities.

The COVID-19 crisis requires innovative approaches to disability inclusive WASH solutions, reaching a group at need. International guidance should continue to be reviewed and updated to better inform

a disability-inclusive approach to COVID-19. EquiFrame itself is a useful tool which can help WASH, health and disability actors to develop new guidance on disability-inclusive COVID-19 and WASH guidance. It has proven a useful tool in reviewing the inclusion of core human rights concepts in existing guidance, and gaps that need to be strengthened.

We must continue advocating for the inclusion of the rights of people with disabilities in the COVID-19 and WASH response, to ensure they are not disproportionately impacted by this global pandemic.



# Annex 1

## 21 Core concepts of EquiFrame, adapted for disability inclusion in the context of the WASH sector

| 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 (e.g. 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 recognize 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 DPOs                                                                                                                                                                                 |
| 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 (interagency) 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 and women/girls 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 or control over what happens to her or him?                                | People with disabilities can express "independence" or "self-determination". For instance, person 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 recognize 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 recognize the value of the family members of people with disabilities in addressing WASH needs?                                                                                                                        | The document recognizes the value of family members of people with disabilities as a resource for addressing WASH needs                                                                                                                                                                                                                                          |
| 14. | Family support          | Does the guidance recognize 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, i.e. 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 |
| 17. | Prevention              | Does the guidance support people with 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 institution, 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 (e.g. 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                                                                                   |

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