

REVIEW

Addressing water, sanitation and hygiene inequalities: A review of evidence, gaps, and recommendations for disability-inclusive WASH by 2030

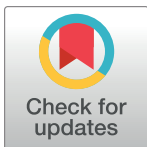
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Abstract

One in six people worldwide experiences significant disability. Many of these people living in low-and middle-income countries (LMICs) are disproportionately affected by inadequate access to water, sanitation and hygiene (WASH) services, a fundamental necessity for health and well-being. This review aimed to examine the existing evidence on disability and WASH in LMICs, identify gaps and make recommendations to strengthen disability-inclusive WASH research, policies and practices to make significant progress by 2030. While evidence of WASH challenges faced by people with disabilities has grown in the last decade, revealing significant inequalities, there is a lack of controlled studies to assess the impact of disability-inclusive WASH interventions. This research gap makes it difficult to prioritise investments for scalable solutions. This review proposes three key recommendations: 1) Further expand research on WASH challenges faced by people with disabilities, prioritising climate risks, health impacts, and educational inequalities. 2) Design and test evidence-based disability-inclusive WASH interventions. 3) Rigorously evaluate these interventions to determine what successfully reduces WASH disparities for people with disabilities and their caregivers cost-effectively. This review is the first to synthesise available evidence across disability and WASH and offer a roadmap for future efforts to drive improvements in disability-inclusive WASH by 2030.



OPEN ACCESS

Citation: Wilbur J, Dreibelbis R, Mactaggart I (2024) Addressing water, sanitation and hygiene inequalities: A review of evidence, gaps, and recommendations for disability-inclusive WASH by 2030. *PLOS Water* 3(6): e0000257. <https://doi.org/10.1371/journal.pwat.0000257>

Editor: Inga T. Winkler, Central European University, AUSTRIA

Published: June 11, 2024

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Funding: The author(s) received no specific funding for this work.

Competing interests: The authors have declared that no competing interests exist.

Background

Disability, exclusion and global development

Globally, 1.3 billion, or one in six people, experience significant disability [1], 80% of whom live in low-middle-income countries (LMICs) [2]. Approximately 110–119 million adults with disabilities rely on caregivers, both informal and formal [2]. Disability, defined as ‘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' [3], increases with age and is more common among women than men [4].

People with disabilities face inequalities in many domains of life, including healthcare, education, employment and access to water, sanitation and hygiene (WASH) services [5–8]. These exclusions deepen poverty and exacerbate disability. Regarding health (including sexual and reproductive health) inequalities, people with disabilities often have a greater need for healthcare but face more significant barriers to accessing services [9]. For instance, this population often require specialised medical assistance (e.g. hearing aids, occupational or physiotherapy) as well as general healthcare services (e.g. antenatal care, vaccinations). Yet, barriers experienced include poverty, limited social support, inaccessible transport, negative attitudes, and inadequately trained staff. Consequently, they experience lower healthcare coverage and worse health outcomes than those without disabilities [6].

Children with disabilities have lower educational enrolment and attainment than those without disabilities, with the most significant disparities in secondary school education [7]. Data from across 30 countries reveals that 30–40% of children with disabilities are not in school, ranging from 17% in Zimbabwe to 78% in Guinea [7]. Adults with disabilities are 50% less likely to be employed than adults without disabilities [2]. Women with disabilities face double discrimination and are less likely to work than men with disabilities [2]. Reasons include lower educational attainment, lack of formal training, and discriminatory social norms that often inhibit women's ability to work outside the home [2, 10].

WASH is fundamental for health and well-being, but people with disabilities have lower access or lower quality access to WASH than those without disabilities [11–13]. Households that include people with disabilities are less likely to have access to basic water and sanitation, resulting in adverse health outcomes [5]. For instance, children with disabilities under five years old are twice as likely to suffer severe diarrhoea compared to their peers without disabilities [5, 6].

Disability-inclusive WASH by 2030: disrupting the poverty and disability cycle

Beyond being a prerequisite to health, WASH also contributes to school attendance, livelihoods, dignity, and poverty alleviation [14]. Increasing access and use of WASH services by people with disabilities should be viewed as an entry point to addressing systemic inequalities faced by this population. This requires coordinated efforts across disability-inclusive WASH, health, education, and livelihoods. Such coordination is already underway for gender equality; for example, increasing access to WASH in schools has been identified as a mechanism for improving educational attainment and gender equality [15]. UNICEF estimates that one in every 10 children worldwide has a disability [16]. Despite this, the first global report on providing disability-inclusive WASH in schools by the Joint Monitoring Programme [17]. Authors note that more countries are monitoring disability-inclusive WASH services in schools but that national definitions and indicators are inconsistent, which makes comparison difficult. However, the report highlights wide disparities between standard and disability-inclusive WASH services: in more than half of all countries where data was available, there was a difference of over 50 percentage points in the availability of basic sanitation facilities compared to disability-accessible toilets. For example, in Yemen, while 80% of schools had toilets, a mere 2% had disability-accessible toilets. The report also highlights the need to gather data on the ability of children with disabilities to use school WASH services without caregiver support. Though a focus on improving disability-inclusive WASH in schools is critical, as many children with disabilities are not in school, efforts must also address barriers to accessing schooling.

Furthermore, WASH services that are accessible for persons with disabilities also benefit people without disabilities who face challenges accessing standard WASH services, such as older adults and people with chronic health conditions [18]. Providing information on WASH in different formats to accommodate various modes of communication and suit different levels of cognition and understanding is vital to ensuring equal access to information. This includes transferring information audibly and visually with images, captioned media, and sign language if required. Such efforts benefit people with disabilities and those without, including those who are less literate, as highlighted by caregivers who attended training in Nepal, where information was provided verbally and visually [19].

In conclusion, disability-inclusive WASH underpins the success of the Sustainable Development Goals, which, in part, aim to enable persons with disabilities to participate in society and be free from poverty. Gains made would also benefit the families of people with disabilities and any other individuals who face challenges accessing standard WASH infrastructure or information.

This review aimed to map out the existing evidence on disability and WASH in LMICs, highlight gaps and make recommendations for improving disability-inclusive WASH policy and practice by 2030.

Barriers to accessing and using WASH services faced by people with disabilities

Historically, the limited evidence base on disability and WASH has contributed to the invisibility and subsequent exclusion of people with disabilities from WASH policy and programming. Over the last decade, evidence about the barriers persons with disabilities face in accessing and using WASH services has increased. Emerging patterns across these data are discussed in this section.

Access to disability-inclusive WASH in households

Data from seven countries show that people with disabilities are less likely to live in households with access to basic water and sanitation [5, 20, 21]. Within their households, they are less able to collect water and use toilets independently, meaning they are more likely to come into contact with urine and faeces [5, 20, 21]. For example, among households with a person living with a disability in Vanuatu, residents with disabilities were more likely than others in their household to experience difficulties feeling safe collecting water, using toilets when needed, and accessing materials to clean the body after toilet use [20].

Evidence has also shown that households and individuals often bear responsibility for developing coping strategies for accessing and using WASH services that are inadequately meeting the needs of people with disabilities. For example, constructing a guide rope from the house to the toilet of a person with visual impairment or piping water to the bed to bathe a person unable to sit out of bed unaided [22, 23]. However, financing these adaptations of existing WASH services to make them more accessible may compound the financial and economic vulnerability of many people with disabilities and their households.

Additional WASH requirements and coping strategies applied

Despite often having worse access, many people with disabilities have a greater need for basic water, sanitation and hygiene than people without disabilities. For example, this includes people with health conditions such as incontinence, Inflammatory Bowel Disease, epilepsy and seizures, albinism, and skin diseases, and people who use orthotics, prostheses or other assistive devices that require cleaning [24–29].

In Vanuatu, a recent study found that people with disabilities are three times more likely to experience incontinence and two times more likely to have faecal incontinence, a highly taboo topic, than people without disabilities [20]. Severity differs across genders and impairment groups: urinary incontinence was more common amongst women with disabilities than their male counterparts, and people with mobility and self-care impairments were more likely to experience faecal incontinence than other impairment groups [30].

Many people with and without disabilities face challenges managing incontinence. All people with incontinence require a toilet that can be reached quickly, additional water and soap to bathe, do laundry more regularly and rehydrate, and many need incontinence products (e.g. mattress protectors, absorbent underwear) that require washing. Yet, evidence from Vanuatu, Pakistan, Bangladesh, Ghana, Uganda, and Malawi highlights that affected individual's ability to manage is severely limited by 1) the distance to latrines, 2) the lack of assistive devices and products that support independence (e.g. raised toilet seats, commodes, bedpans) and 3) absence of incontinence products [30–32].

Coping strategies applied by people with disabilities and caregivers involve limiting the intake of food and water, heavy reliance on soap and water when available for maintaining personal hygiene, and use of locally available resources to manage leaks, including laying plastic bags on a bed as a mattress protector, limiting social interaction and leaving home and in some instances, banishment from the family home [30, 31]. Regarding inaccessible latrines, some people use 'bucket latrines', which cause significant safety and health risks: the user may fall off the bucket and injure themselves, and all household members are exposed to pathogens in faeces when the bucket latrine is used, emptied and cleaned. These issues, including disability discrimination, meant that people with disabilities experienced more significant challenges managing incontinence and, therefore, more adverse outcomes than those without disabilities [30].

Reliance on caregivers

Many people who rely on caregivers have mobility, cognition, or self-care limitations that affect their ability to manage their WASH requirements independently. Informal family caregivers frequently provide such support in many LMICs. WASH support provided to people with disabilities by caregivers often entails collecting water, toileting, and personal hygiene, including handwashing, bathing, supporting menstrual health, and laundry [21, 33, 34].

Evidence from several settings highlights a significant lack of attention to caregivers' vital role in supporting people with disabilities to meet their WASH requirements and participate in daily life. Analysis of Nepal, Bangladesh, and Cambodia's WASH-related policies and guidance, using a modified version of the EquiFrame content analysis tool, shows that caregivers are consistently absent in these documents [35, 36]. This omission translates into practice. Evidence exploring experiences of people with disabilities reliant on caregivers for their WASH requirements consistently highlights that caregivers have no guidance or support about providing WASH care in a safe, dignified and hygienic way. A study in Malawi found that caregivers of people with disabilities ranked bathing, laundry, soap availability, getting to the toilet, managing urine and defecation and disposal, and getting enough water for their WASH support tasks as their most significant daily challenges [33]. Non-WASH concerns comprised feeding and challenges specific to the impairment experienced, such as seizures, information and communication.

Evidence from Nepal, Pakistan, Cambodia and Vanuatu reveals that caregivers rarely have lifting devices, so they must move people manually for toileting and bathing. Consequently, they regularly report associated back and shoulder pain, sleep deprivation, fatigue, and worry for the future care of the person with disabilities if they are unable to carry out the role [22, 23,

30, 31, 34]. As children grow up and become heavier, some caregivers limit the person with disabilities' food so that they are lighter to lift. Evidence outside WASH identifies people with physical disabilities, particularly those with cerebral palsy, as being at a higher risk of malnutrition due to feeding difficulties and weight gain, and consequently premature death [37, 38].

Caregivers must often balance or choose between providing full-time care if required, and earning an income. In Pakistan, caregivers described selling livestock and wedding jewellery to fund incontinence support [31]. A study exploring the menstrual health experiences of people with intellectual disabilities and their caregivers in Vanuatu's humanitarian emergencies found that a person's support requirement often increased during and after a disaster [39]. This meant caregivers were less able to earn an income to rebuild their house and recover before the next humanitarian crisis, thus pushing the household further into poverty. Consequently, many people with disabilities feel like burdens and internalise disability stigma and discrimination [30, 34, 39, 40].

Cumulatively, these issues negatively impact the person with disabilities and the caregiver's mental and physical health and well-being [22, 23, 33–36, 39, 41–45].

Many people with disabilities and their caregivers cannot leave their home

Many people with disabilities are unable to leave home to attend school, work, or social events because of multiple factors. This includes inadequate access to assistive devices (e.g. wheelchair, walking cane), inaccessible transport, environment, and reliance on caregivers. Disability discrimination also plays a significant role. Across 30 countries, the most frequently cited reason for not attending school was 'having an impairment' [7]. In Malawi, people with intellectual disabilities were often excluded from social events because they were perceived as not being able to understand information or that they would disrupt the process [33]. Caregivers providing full-time care also find it very difficult to leave home. Yet, many WASH interventions are delivered in communities or schools, and minimal efforts are made to support people with disabilities and their caregivers to attend or provide outreach to people's homes for those unable to leave [22, 23, 34, 35]. In Nepal, caregivers reported missing out on menstrual health interventions delivered in their communities, making them less informed about the topic for themselves and the person they support [34]. Service providers also explained that children with disabilities do not participate in school menstrual health interventions, citing a lack of representation in school and limited personal knowledge about disability [35].

Menstrual health for people with disabilities

Attaining menstrual health involves affordable menstrual materials, WASH facilities for hygiene, medical support, and a stigma-free environment. Access to information, resources, and a supportive environment is essential for overall well-being during menstruation [46]. Even though an estimated 12% of women of reproductive age have a disability, an increasing body of evidence demonstrates that women and girls with disabilities face layers of additional challenges in achieving menstrual health in development and humanitarian settings [41, 42, 47, 48]. Barriers encompass being excluded from menstrual health policy and practice, encountering inaccessible WASH facilities (including disposal mechanisms for menstrual materials), and lacking guidance for caregivers to perform menstrual health support [34, 35, 39, 40, 49–53]. Women and girls with disabilities, particularly those with intellectual disabilities, may endure severe consequences such as physical restraint, abuse, and sterilisation due to insufficient menstrual health support [54–56].

Neglect of sexual and reproductive health for people with disabilities (which includes menstrual health) is evident, as shown in Hameed et al.'s systematic review [57]. Only 5% of 400

identified studies on sexual and reproductive health for people with disabilities focused on interventions to improve this, the majority of which were in upper-middle-income countries and urban settings. The reported interventions focused primarily on information provision, with few evaluating effectiveness. Arguably, sexual and reproductive health for people with disabilities is often neglected due to discriminatory beliefs, such as the misconception that they are asexual or lack reproductive capabilities, including menstruation and childbearing [2, 6, 58, 59].

The data illustrates the presence of multiple power systems across diverse social settings, evident in shared experiences like menstruation-related participation restrictions and various forms of violence. Applying an 'intersectionality' lens reveals how factors like disability, gender, age, and sociocultural norms intertwine as forms of oppression and discrimination within menstrual health. Considering broader social and structural influences is crucial in understanding menstrual behaviours.

Disability-inclusive WASH interventions and evaluations

Inclusive WASH definition and guidance

Inclusive WASH is an approach that addresses barriers faced by individuals vulnerable to exclusion when accessing and using WASH services [30]. Regarding disability, inclusive WASH ensures the effective participation of people with disabilities in research, policy, and programme design. They and their caregivers can access and comprehend information tailored to their WASH requirements, dispelling misconceptions. Safe, dignified access to WASH services is achieved by enabling people to reach and use the WASH services independently or with support from caregivers. Adaptations include guide ropes or landmarks to facilities, hand and grab rails to support balance, raised toilet seats, water inside the latrine or bathing facility to support personal and menstrual hygiene, accessible disposal mechanisms for menstrual and incontinence materials and space for a caregiver to assist if required [60]. Policies and interventions include disability-specific activities; they are monitored and reported with active and meaningful involvement of people with disabilities. This definition aligns with the inclusive systems-based thinking approach required for sustainable and resilient WASH services and systems [61].

Resources to support the implementation of disability-inclusive WASH policies and practices are growing. The EquiFrame, a policy analysis framework, is used to evaluate policy commitment to 21 human rights principles and the inclusion of 12 'vulnerable' groups, including persons with disabilities and women and girls. The EquiFrame was adapted for WASH, menstrual health, disability, and gender and applied across four studies that enable a comparison of results [35, 36, 45, 62]. Based on the human rights principles detailed in the adapted EquiFrame, the evidence-based Disability-Inclusive WASH Checklist was designed for government officials and service providers [63]. It facilitates the inclusion of individuals with disabilities and caregivers in national policies and interventions by identifying specific activities that can be incorporated to enhance disability inclusion within the planning, implementation, monitoring, and evaluation. Similarly, the *Disability Inclusion and COVID-19: Guidance for WASH Delivery* and the *COVID-19 Inclusive WASH Checklist for including disability and ageing in WASH* checklists support service providers to deliver interventions that include people with disabilities, older adults, and caregivers [64, 65].

Further resources exist to support the design and implementation of disability-inclusive WASH interventions, including the Gender Equality and Social Inclusion Self-Assessment Tool [66], ideas about facilitating inclusive processes and making WASH services more

accessible using low-cost options [67–69], guidance and information about incontinence [70], and how to support people with disabilities personal hygiene requirements at home [71].

Regarding menstrual health, the Socio-ecological Framework for Menstrual Hygiene Management, which has been tested and applied in different LMICs [72–74], was adapted to incorporate disability and caregiving in 2019 [75]. With the publication of the Integrated model of menstrual experience in 2021 [46], the framework was further adapted and applied to explore the inclusion of disability in menstrual health efforts during humanitarian emergencies [42]. It can be used as a conceptual framework to inform research, policy and practice for inclusive menstrual health and hygiene.

Interventions and evaluations

Disability-inclusive WASH interventions. Targeted funding for designing and delivering disability-inclusive WASH has led to increased interventions to improve access to and use of WASH services for people with disabilities in LMICs. For example, the Australian Department of Foreign Affairs and Trade's Water for Women's fund invested AUD 154.9 million over seven years in supporting inclusive and sustainable WASH research and interventions in Asia and the Pacific between 2018 and 2024 [61]. However, the majority of disability-inclusive WASH interventions delivered by civil society organisations have yet to be assessed in an appropriate way to understand the impacts on the lives of people with disabilities.

Two promising projects delivered by WaterAid and World Vision in the Pacific region require evaluation to understand if interventions warrant further investment. In Papua New Guinea, WaterAid supported the East Sepik Disabled Persons Association, a small disability organisation, enhancing its funding, governance, and WASH advocacy [61]. The organisation now promotes disability-inclusive WASH, leads awareness workshops, and gathers community data with WaterAid. In 2019, the London School of Hygiene & Tropical Medicine and World Vision completed a disability survey in Vanuatu that assessed disability prevalence and access to WASH and explored experiences of menstrual health and incontinence, integrating a gender perspective [20]. This study informed the development of World Vision's Disability-inclusive WASH interventions. These were designed and delivered with national disability service providers. Inclusion strategies involved disability awareness training, co-developing individualised plans for improving more independent access to WASH at home, the production and distribution of locally sourced commodes, inclusive latrines, and personal care products (e.g. mattress protectors, wash mitts, reusable incontinence products), providing guidance for caregivers, and incorporating disability-inclusive planning and preparedness for disasters [61].

Feasibility studies. Conducting feasibility studies is an essential initial phase in systematically assessing evidence to determine whether an intervention is worthy of further efficacy testing [76–78]. A good example of how feasibility studies are being used to inform evidence-based disability-inclusive WASH design is in menstrual health.

Growing efforts to support the menstrual health of people with disabilities are increasing with interventions tailored for different impairment groups, including visual and intellectual [19, 79–82]. Encouragingly, findings from feasibility studies conducted on menstrual health behaviour change campaigns in Vanuatu's humanitarian responses and Nepal's development setting show that people with intellectual disabilities understood the intervention content and applied learning and that caregivers (both male and female in Vanuatu) were better equipped to support after the campaign [19, 79]. The Bishesta campaign in Nepal had unintended effects, fostering increased confidence in young people managing menstruation and altering parental perceptions of maturity. In Vanuatu, caregivers used the Veivanua campaign resources to teach young women bodily awareness and social skills. Consequently, the authors

highlight that these initiatives serve as potential starting points for broader self-care assistance for women and girls with intellectual disabilities [79].

The campaigns have proven feasible within a limited sample size, but they now require efficacy testing with a larger sample before scaling up. The intervention should also be adapted to support the menstrual health of people with physical, visual, hearing, and communication impairments.

Evaluations. In 2021, an evidence gap map presented data from systematic reviews and impact evaluations of what works in WASH interventions in LMICs [83]. A significant result was that the authors did not find any controlled studies that assessed the impact of WASH interventions on individuals with disabilities or reported the impact of standard WASH interventions on this population and other groups that may be vulnerable to exclusion. The authors made urgent calls to address this critical evidence gap. Moreover, better quality evaluation research is required to robustly establish which interventions improve disability inclusion in WASH.

Recommendations

Three overarching recommendations for improving disability-inclusive WASH policy and practice by 2030 are provided below. These should be guided by the definition of disability-inclusive WASH, including meeting the requirements of specific impairment groups. Importantly, activities must involve organisations of persons with disabilities and reduce disability discrimination and institutional and structural barriers to participation that people with disabilities often internalise. All efforts to increase disability-inclusive WASH must be interlinked with other sectors, including disability support, health, and education, for more comprehensive gains. All recommendations are relevant for development and humanitarian settings.

1. Expand understanding of the requirements and challenges faced by people with disabilities and their caregivers when accessing and using WASH services and information.

Even though the evidence is increasing, gaps remain, especially concerning the following topics:

- a. *Climate change:* People with disabilities are at greater risk from climate hazards because of pre-existing inequalities, including barriers to participating in public life and accessing WASH services and critical safety information during climatic events [84–86]. Nevertheless, studies to understand how climate risks to WASH impact people with disabilities and developing and evaluating evidence-based solutions to address these are nascent in scientific research.
- b. *Impacts of inadequate WASH on health and well-being:* Studies of minimum water requirements for drinking and personal hygiene have considered the needs of populations with specific hydration requirements (e.g. lactating women, older adults, people with acute diarrhoea, and those who are terminally ill or fasting, especially in hot climates), but have overlooked the complex needs of people with disabilities and their caregivers as outlined in this paper [87]. Additionally, studies on water insecurity have investigated the issue at the household and individual levels to understand related gendered impacts [88–90], but none have considered this in the context of people with disabilities. This requires more exploration and should be part of broader efforts to capture experiential aspects of WASH.

Secondly, data from many settings highlight that people with disabilities and their caregivers are more likely to come into contact with urine and faeces than those without disabilities. Yet, data on the related health consequences to inform appropriate interventions are missing. In-depth research is needed to understand the risks of contracting WASH-related illnesses such as diarrhoea, trachoma, soil-transmitted helminths

- and schistosomiasis among people with disabilities and (where applicable) their caregivers, compared with others.
- c. *Access to disability-inclusive WASH in schools*: Research exploring the barriers to accessing and using WASH infrastructure and information in schools and at home for children with and without disabilities should be conducted to understand educational and WASH inequalities and inform strategies to address these. These activities should be combined with interventions targeting educational access and attainment among children with disabilities, particularly in recognition of the role WASH plays in both.
2. **Develop and pilot test evidence-based disability-inclusive WASH interventions**: Drawing on existing evidence set out in this review and new data that will be generated from completing the recommended studies above, interventions to address the challenges faced by people with disabilities and their caregivers should be developed and pilot-tested. The intervention design should follow the twin-track approach, which outlines a method to facilitate inclusive development [91]. Disability-specific WASH interventions are implemented alongside the integration of disability considerations into mainstream WASH programmes. This could include completing a feasibility study to understand if further investment is warranted.
 3. **Evaluate disability-inclusive WASH interventions**: This review has documented increased data across different settings that show the barriers people with disabilities face in accessing and using WASH services and interventions delivered to address these. Urgent investment is required to evaluate these efforts and understand their effectiveness. Drawing on Chirgwin et al.'s recommendation, this should be coupled with meta-analysis pooling to merge data from various studies.

Conclusion

This review outlines the evidence about disability and WASH in LMICs. Emphasising the current evidence base and identifying key evidence gaps, it provides recommendations to enhance disability-inclusive WASH policies and practices to achieve substantial improvements by 2030.

Over the last decade, evidence about the challenges people with disabilities face when accessing and using WASH services and the impacts of these challenges have increased. Data reveals substantial WASH inequalities experienced by this population and their caregivers. Supportive resources for implementing disability-inclusive WASH policies and practices are growing, as are interventions to realise these. However, there is limited or no data from many settings globally, and no controlled studies exist that assess the impact of disability-inclusive WASH or standard WASH interventions on people with disabilities and their caregivers. Without rigorous evaluations, it is challenging to understand which interventions warrant further investment for scalability.

This review makes three overarching recommendations which build upon each other. Firstly, increase evidence to understand better the challenges faced by people with disabilities and their caregivers when accessing and using WASH services and information. Priority topics are understanding 1) the impacts of climate risks to WASH, 2) the impacts of inadequate WASH on health and well-being, and 3) inequalities in education and WASH for children with disabilities. Secondly, to design and pilot test evidence-based disability-inclusive WASH interventions and, finally, to evaluate these efforts to understand what reduces inequalities in WASH for people with disabilities and their caregivers.

Regarding limitations, this review draws on a relatively small pool of evidence generated by the few academics focused on this topic. If the focus on disability-inclusive WASH increases,

there is an optimistic expectation for a substantial expansion of this dataset. Despite the limitations in available data, this is the first review to amalgamate evidence across disability and WASH. Therefore, it offers a crucial springboard for future research, highlighting critical gaps and proposing a roadmap that can guide improvements in disability-inclusive WASH policies and practices by 2030.

Author Contributions

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