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

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ABSTRACT

The critical importance of unrestricted access to clean drinking water and basic sanitation for all is highlighted in Millennium Development Goal 7, which calls for the reduction by half of the proportion of people without such access by 2015. Unfortunately, little attention has been paid to the needs of such access for the one billion people living with a disability worldwide, despite the fact that the right to equal access for all international development initiatives is guaranteed in the new United Nations Convention on the Rights of Persons with Disabilities. In this paper, we review what is currently known about access to water and sanitation for persons with disabilities in low- and middle-income countries from the perspective of both international development and global health, and identify existing gaps in research, practice and policy that are of pressing concern if the water and sanitation needs of this large – and largely overlooked – population are to be addressed.

Key words | disability, health, hygiene, poverty, sanitation, water

INTRODUCTION

The global burden of disease resulting from poor access to water and sanitation facilities is often measured in DALYS (disability-adjusted life years). However, the short- and long-term implications of lack of access to clean water and basic sanitation faced by millions of persons already living with physical, intellectual, sensory (blindness, deafness) or mental health impairments are not routinely discussed or evaluated. Nor are there much data on the social, economic or health implications that this lack of access might have on the health and well-being of these individuals, their families and their communities. The growing body of data firmly linking persons with disabilities to extreme poverty and social marginalisation gives clear cause both for concern and for the need to ensure that persons with disabilities are systematically included in all water, sanitation and hygiene (WASH) efforts.

Millennium Development Goal 7 Target C is to halve the proportion of the population without access to clean water and basic sanitation by 2015 (UN 2000). According to the UN, an estimated one billion individuals, roughly 15% of the world’s population are persons with disabilities (WHO 2011). Presumably, if persons with disabilities make up 15% of the world’s population, then they also comprise roughly 15% of all those reflected in such statistics. Thus Goal 7 Target C will not be achieved unless persons with disabilities are routinely included in water and sanitation programmes (Groce & Trani 2009).

Such access is a right also guaranteed under the new UN Convention on the Rights of Persons with Disabilities which came into force in May 2008 (UN 2006). Article 9 of the Convention specifically ensures persons with disability equal access to the physical environment and the identification and elimination of all obstacles and barriers to such accessibility; Article 28 recognises the right of persons with disabilities to an adequate standard of living for themselves and their families, including adequate food, clothing and housing, and
Article 32 ensures that international cooperation, including international development programmes, are inclusive of and accessible to persons with disabilities (UN 2006).

This paper reviews the existing knowledge of water and sanitation as it relates to persons with disabilities. We will argue that a small but growing body of writings in the engineering and disability advocacy fields now makes knowledge of low-tech, low cost interventions for persons with disabilities increasing more available. However, this information has yet to be widely disseminated among WASH professionals or incorporated into routine WASH policies and practices and the potential health and development implications of this lack of access to adequate water and sanitation facilities remains largely unexamined. We also note with concern that in some places, improvements in WASH facilities – new latrines with steps, or water pumps with higher handles – may in fact make new WASH facilities less, not more, accessible to people with some types of disabilities. Thus this paper is also intended to provide an overview and an introduction to key issues in global disability, identifying where gaps in knowledge currently exist and make recommendations for future research and programming.

In the course of this desk study, the public health and medical literatures were reviewed through Medline, Web of Science and Global Health search engines, paying particular attention to any epidemiology or disease-specific studies linking disability to water-related morbidity or mortality. The grey literature was also reviewed, with particular attention paid to publications from major UN agencies, bilateral and multilateral organisations, non-governmental organisations (NGOs) and disabled peoples’ organisations (DPOs) working on health and development issues. While we were interested in any publications relating water and sanitation to health and disability, emphasis was placed on articles published between 1995 and the time of the review (2010) and on publications which focused on low- and middle-income countries, as defined by the World Bank (2010).

**BARRIERS TO ACCESS**

It is a widely acknowledged but little studied fact that persons with disabilities routinely face difficulties in accessing clean water and basic sanitation throughout the developing world. Issues preventing disabled people from accessing water and sanitation in these countries may vary depending on cultural and geographical contexts, as well as by the type of disability a person may have. Thus a person with a physical impairment may face significantly more difficulties in using a hand pump or an outdoor latrine, a person who is deaf or who has an intellectual disability may have no physical difficulty in walking to a community latrine, but be teased or abused and thus find such a facility inaccessible for social and safety reasons. However, cultural and geographic variations, as well as adaptations needed for persons with different types of disabilities, are well known and can be anticipated and planned for. Pradhan & Jones (2008) argue that these barriers can broadly be separated into two types: technical and social.

**Technical barriers**

Technical barriers include the structural difficulties faced by persons with disabilities in accessing water and sanitation facilities. For example, many people with physical impairments are unable to collect water for themselves. Some cannot carry water the distance required, others find wells too high (Tesfu & Magrath 2006; WaterAid 2006; Pradhan & Jones 2008).

Even if persons with physical disabilities are able to carry water, they may not be able to carry the amount they need (Kendra 2008), and reports from the field collected by the Leonard Cheshire Disability and Inclusive Development Centre, University College London (Bailey & Groce 2009) indicate that even in the hottest climates, individuals with physical disabilities report restricting the amount of water they use or consume because of the inability to transport needed amounts back to their households. Persons with physical disabilities also report that carrying water can be exceptionally time consuming – either for themselves or for the person collecting water on their behalf (Jones et al. 2003; Snider & Takeda 2008).

As collection of water is often an activity undertaken by one or two members of the family on behalf of the others, many studies have found that people with disabilities reported more difficulties accessing sanitation facilities than collecting water (Kendra 2008; WaterAid Nepal 2008). Hardware and washroom doors can be difficult to
Water and sanitation issues for persons with disabilities

Barriers to persons with disabilities extend beyond design and hardware issues. Social barriers vary in different cultures; however, studies from many countries report that persons with disabilities often face stigma and discrimination from others when using both household and public facilities. Fears that persons with disabilities would contaminate water sources or that they would make the latrines dirty are frequently reported (Rukunga et al. nd; Tesfu & Magrath 2006; Pradhan & Jones 2008).

People with certain types of disabilities may also need to take a longer time to use the facilities – a stigmatising experience when using communal latrines (Kendra 2008). Others who are unable to enter latrines (or who did not use latrines due to discrimination from their communities) have raised the issue of stigma associated with open defecation, resulting in disabled people (particularly women) only going in the dark, with the attendant dangers of accidents, rape and other adverse safety issues (Snider & Takeda 2008; WaterAid Mali 2007; Gosling 2010).

Many of the studies currently available note the low self-esteem and lack of dignity experienced by those who are dependent on family members to assist them in using inaccessible water (and particularly sanitation) facilities (Hannan 2005; Tesfu & Magrath 2006; Flowers 2009). The issue of time allocation within families is also frequently raised by persons with disabilities who require assistance because of inaccessible facilities. This may compound negative attitudes already existing in families where a disabled family member is perceived as a social or financial burden (NEWAH 2004; Snider & Takeda 2008). Accessible latrines can make a significant difference in a disabled person’s self-esteem, in attitudes towards them within their household and in their community (Rukunga et al. nd; WaterAid Ethiopia 2008). They also appear to increase the time available for disabled people themselves and/or their care-givers to engage in productive activities, rather than expending inordinate amounts of time on mundane water and sanitation chores (Hannan 2005; Jones & Reed 2005).

Although most of the studies on disability issues and water and sanitation focus on the individual’s home and community, a few also discuss the implications of lack of access to water and sanitation facilities in school and in the workplace (Menya & Safu 2005; Musenyente 2005; Lewis 2010). Studies find that children with disabilities are often prevented from attending schools due to a lack of accessible toilets (Menya & Safu 2005; Bah 2010). For example, in Uganda, efforts to increase enrolment of disabled children in schools through inclusive education programmes and legislation are being undercut by lack of accessible toilets, with particularly high dropout rates reported among physically disabled adolescent girls who
were unable to access school toilets modestly (Bailey & Groce 2010). In an era when UNESCO reports that more than 90% of all disabled children still do not attend school, and disabled girls are far more likely than boys to leave school early (UNESCO 2010), it seems particularly unfortunate that disabled girls are dropping out of school because they cannot get into the school bathroom and close the door behind them.

Employment is an area of equal concern. Unemployment rates globally for persons with disabilities range above 80% (UN Enable 2008). Lack of accessible toilets is often a critical barrier to persons with disabilities seeking and taking jobs (Snider & Takeda 2008).

Nor is this a barrier for persons with disabilities alone. The need for assistance in toileting and care is regularly cited as the reason that one or more adults in a household (usually the mother) remains at home rather than participating in the workforce (Jones & Reed 2008). Where disabled children are in schools with no accessible toilets, it is also not unusual to have mothers stay home from work or leave chores and other children at home to walk to their child’s school several times a day to help with toileting activities (Achieng 2010; Lewis 2010).

Thus equitable and accessible access to water and sanitation affects all household members. Where lack of accessible water and sanitation facilities limits a child’s ability to get an education or keeps both a disabled individual and a carer out of the workforce, the economic impact on families in compounded. Because the carer is usually a woman, this is also a gender issue. With lower earning potential, such families may also be unable to afford to make structural adjustments to home water and sanitation facilities to increase access and in the end, persons with disabilities who remain uneducated and unemployed often have less ability to influence decisions made within their families and communities, including decisions about water and sanitation facilities (Pradhan & Jones 2008; Snider & Takeda 2008).

TECHNICAL KNOWLEDGE AND EXPERIENCE

While there is limited work on the adaptation of water and sanitation systems, a growing number of very good resources are now available. Of note is work at the Water Engineering and Development Centre (WEDC) at Loughborough University in the UK, where Jones and Reed’s DFID-funded research on ‘Water Supply and Sanitation Access and Use by Disabled People’ from 2002 and 2005 produced significant contributions to the literature. On-going work by Jones and her colleagues continue to contribute on-line and published resource (Jones & Fisher 2008).

In recent years, additional studies, reports and manuals from WaterAid, the World Bank as well as NGOs and DPOs have begun to provide water and sanitation experts with good technical information on how to include persons with disabilities (see for example NEWAH 2004; Ferneeuw 2005; Jones & Reed 2005; Jones & Jansz 2008).

Aside from structural solutions developed by these researchers, there is a consensus in this literature that:

1. there continues to be a lack of relevant information and documented examples of good practice;
2. barriers to access arise from obstacles in the built environment, social barriers and institutional factors, as well as individual abilities, and this range of barriers needs to be addressed holistically;
3. it is more cost-effective to design accessible facilities from the outset than to make changes later;
4. although many governments and international agencies have policies and legislation about the inclusion of persons with disabilities, these almost never include WASH concerns;
5. WASH professionals and advocates need training on disability issues to ensure they include persons with disabilities in consultations and do not see disability as a separate ‘specialist’ issue;
6. women with disabilities often face double or triple discrimination, and their needs are often completely overlooked; and
7. it is essential to include persons with disabilities in decision-making processes from the outset in order to ensure the resulting solutions will be effective.

Jones & Jansz (2008) have discussed the merits and risks of two different approaches to improving accessibility: (1) starting with a group of people with a specific impairment, identifying problems and needs, and developing solutions to address these individual needs; or (2) starting
at the community level, identifying problems in accessing existing services for all people and developing solutions to eliminate common obstacles. The first approach focuses on solving individual problems effectively, but limits applicability to other users and risks segregating users – it largely involves developing individual accessibility aids.

The second approach is more holistic, reflecting the concept of ‘Universal Design’ and involves changing the infrastructure. Universal Design increases accessibility for more people but may not meet the needs of all users (Montgomery et al. 2009; Universal Design Network). A middle ground, where community level WASH facilities are made universally accessible, but with the acknowledgement that in some cases additional adaptations may be needed for individuals with specific needs, might be the best solution.

Health implications of lack of access to water and sanitation

While technical and social implications of access to water and sanitation have received some attention in recent years, the health implications have not been documented specifically for persons with disabilities.

Particularly absent in our review of the literature was any information on exposure linked to morbidity or mortality as a result of lack of access to water and sanitation facilities for persons with pre-existing disabilities. This lack of focus on the health of persons already living with a disability is common across a number of public health arenas. Limited research exists, for example, on general paediatric care for disabled children or HIV/AIDS rates among persons with disabilities. Thus the lack of information on the links between persons with disabilities and water-related illness issues does not come as a complete surprise.

In lieu of such data however, we here summarise estimates on the global burden of disease attributable to water and sanitation worldwide from a disability perspective. Pruss-Ustun et al. (2008) estimate that poor access to water, sanitation and hygiene is responsible for 4% of global deaths and 10% of the total disease burden (in DALYs) worldwide. The World Health Organization has estimated that 1.8 million people die every year from diarrhoeal diseases (90% of whom are children under five in developing countries), and 88% of these diarrhoeal deaths can be attributed to an unsafe water supply and/or inadequate sanitation and hygiene (WHO 2004). It has been estimated that improved water quality reduces diarrhoea morbidity; point-of-use household water treatment and improved sanitation leading to reductions in diarrhoeal disease of 35% and 32%, respectively (Fewtrell et al. 2005).

The health risks of limited access to water and sanitation are broader than those of infectious diseases alone. Reports suggest that when persons with disabilities need assistance to use the toilet, individuals may significantly restrict their intake of both water and food throughout the day, waiting until evening to ensure that a member of the household is nearby to assist them with toileting activities (Bailey & Groce 2009). In hot climates, restriction of water during the day may have significant health implications. In many countries, restricting food to one meal a day may lead to serious under-nutrition or malnutrition in individuals who may already be nutritionally compromised due to disability-related health concerns (Yousafzai et al. 2003).

The difficulty in accessing sinks or enough water to wash properly after trips to the toilet is also reported regularly by persons with disabilities and this is likely to put them at increased risk of disease (Tesfu & Magrath 2006; WaterAid 2006). The link between poverty and disability also means that many persons with disabilities may live in households where they are unable to afford soap and other cleaning materials.

Nor are diarrhoeal diseases, nutrition and lack of soap and clean water the only concerns of persons with disabilities. An estimated 2 billion nematode infections could be averted along with 200 million fewer individuals suffering from cases of schistosomiasis and 5 million fewer cases of visual impairment due to trachoma, by providing access to clean and safe water and sanitation supplies (Pruss-Ustun et al. 2008). Trachoma, the world’s primary cause of preventable blindness, is particularly relevant to this discussion because it represents an example of how lack of access to sanitation and hygiene actually induces a disability (irreversible blindness), further compounding the already difficult situation faced by individuals with pre-existing disabilities, while adding to the total numbers of individuals living with a disability in those communities at risk of the disease. Field research in Tanzania demonstrated that use of a simple pit latrine reduces risk of trachoma by half.
(Montgomery et al. 2010), but many such latrines continue to be inaccessible to persons with disabilities, and the necessity for many people with physical disabilities of having to crawl to the latrine area or across latrine floors, would only increase this risk of exposure.

When discussing direct effects of water supply on health, Cairncross stresses that the quantity of water available is far more important than quality of water, as ‘practically all potentially water-borne infections that are transmitted by the feco-oral route can potentially be transmitted by other means (contamination of fingers, food etc.) all of which are water-washed routes’ (Cairncross & Valdmanis 2006).

It can be assumed that persons with disabilities are at least at equal risk of exposure to any and all of these infectious diseases and equally likely to benefit from interventions. Indeed, although research on this is only now underway (Bailey & Groce 2010), it can be speculated that individuals with mobility impairments who must crawl across ground or through water contaminated by faecal matter, may be at increased risk of exposure to a number of infectious diseases such as schistosomiasis, trachoma and intestinal worms. Furthermore, while we can assume that persons with disabilities are at equal or increased risk of exposure to such diseases, there is a growing body of data that clearly show that should persons with disabilities become infected, they are far less likely than their non-disabled peers to have timely access to medical care – or any access at all.

In cultural settings where women are only able to defecate and urinate in the dark, Cairncross suggests that an increased prevalence of urinary tract infections is likely (Cairncross & Valdmanis 2006). This is relevant to those persons with disabilities already at increased risk of urinary tract infections who are unable to use latrines during daylight hours due to accessibility issues or stigma. Additionally, individuals with physical, intellectual, mental health and sensory (blindness/ deafness) disabilities routinely report incidences of physical, verbal and sexual abuse when using public facilities (Groce 2006).

Poverty and lack of access to water and sanitation

Lack of access to water and sanitation has significant economic as well as health implications. Persons with disabilities and their families are disproportionately poor (Elwan 1999). Furthermore, a growing body of research indicates that the interplay between disability, poverty and health is multidimensional, thus making intervention to alleviate or eliminate such poverty, more complex than initially anticipated and including issues such as health, education and access to resources like water and sanitation (Braithwaite & Mont 2009; Mitra & Sambamoorthi 2009; Mont & Loeb 2008; Trani & Loeb 2011).

The link between poverty, disability and access to water and sanitation resources, particularly in communities with improving economic resources, needs to be considered. The economic justification for ensuring access to water and sanitation facilities for persons with disabilities has yet to be adequately addressed in the literature, but the association between poverty and impediments to clean water and basic sanitation is clear. Worldwide, the lowest quintile is 16 times more likely than the wealthiest to practice open defecation: while the majority of the poorest practice open defecation (63%); the wealthiest do not (4%) (Bongartz & Chambers 2009; WHO/UNICEF 2010). Cairncross and colleagues have already established a solid link between improved water and sanitation facilities and economic benefits, as time previously spent transporting/queuing for water can instead be spent earning money (Cairncross & Valdmanis 2006). Hutton et al (2007) report that in Sub-Saharan Africa there is at least a US $5 benefit for every US $1 investment in water and sanitation. Such arguments are particularly relevant for persons with disabilities and their households. Those with disabilities and their families fall disproportionately into the poorest quintile and thus may be assumed to be disproportionately represented among those most in need of improved water and sanitation interventions. Campaigns and initiatives to improve community-wide access to improved water and sanitation and to eliminate WASH associated diseases simply will not succeed if persons with disabilities are not reached as part of the general population.

If a disabled person can access water and sanitation facilities without assistance from a family member, then the person with a disability and the family members can use their time more productively both at home and in the workplace (Hannan 2005; Jones & Reed 2005). Thus latrine ownership – or lack thereof – may have an even greater
impact on the economic and social status of a person with a disability, particularly if it means they are better able to not only maintain their dignity but also to have the time and energy to engage more effectively with the surrounding community.

**CURRENT GAPS IN KNOWLEDGE**

Data on disability prevalence, on disability within the broader realm of international health and development efforts, and specifically within the realm of water and sanitation, are currently exceptionally limited throughout the developing world. Data on disability and development issues have only recently begun to be collected—much of it in response to the new efforts called for by the UN Convention on the Rights of Persons with Disabilities (UN 2006) and the work of the UN’s Washington Group on Disability Statistics (Washington Group 2010).

Information on the access of persons with disabilities to water and sanitation is largely anecdotal or based on small-scale, largely qualitative studies. Such studies are usually initiated to identify need or document technical solutions in a specific community, and can represent important new contributions to the literature (see for example: David; Ferneeuw 2005; Sinha *et al.* 2006; Horne & Debeaudrap 2007; Jenkins 1999; Russell 2008; Taylor 2009). However, the next step is for implementation and evaluation of such interventions on a larger scale with rigorous longitudinal assessments, in order to better identify what works, why it works and what the actual benefits are to persons with disabilities and their family.

More studies are also needed documenting good practice and innovative examples of adaptations that are low cost, locally implemented and sustainable over time. There is likewise a need to investigate intermediate measures (e.g. the use of pots of water for washing or adaptations for toileting) used by households when they cannot afford or have been unable to implement structural changes. We anticipate that many adaptations will be simple ones, for example the use of ropes or fences to help guide persons with visual impairments to household wells or latrines, support bars or hand rails made from local materials such as wood or bamboo, or the use of adaptive clothing (such as the replacement of buttons with Velcro or draw strings). Other adaptations will be more costly, such as building latrines with concrete floors to allow clean, non-slip surfaces or putting in wider doorways. Finally, additional information is needed on how and to what extent persons with disabilities rely on other household members for assistance, and how this impacts relationships within families and households, as well as the economic and social implications this represents.

The health implications of restricted access to clean water and basic sanitation, as noted earlier, are anticipated to be significant in terms of infectious and water-borne diseases, psychological issues and safety concerns for both men and women, but almost no research currently exists on this subject. Furthermore, while implications can be deduced from more general studies, it is likely that some health outcomes will be different for persons with different types of disabilities. Also, should a person with disabilities fall ill due to restricted access to clean water and basic sanitation, it can be anticipated that in many households—especially in the poorest households—they will be less likely to have access to timely medical treatment. Further research is needed on this as well. Thus it is anticipated here that there may be significant differences in both morbidity and mortality for persons with disabilities with respect to water and sanitation-related diseases. The implications of exposure to these diseases for other household members are worth researching. Our own research centre, the Leonard Cheshire Disability and Inclusive Development Centre at University College London, is currently undertaking a series of such studies, but far more work is needed on this subject.

**Next steps**

Research on the ramifications of access and lack of access to safe water and basic sanitation for persons with disabilities is needed at all levels. In order to create an evidence base, questions about persons with disabilities should routinely be included in all studies on water, sanitation and hygiene practices. It would be equally beneficial to include questions about water, sanitation and hygiene practices in disability and development research projects. This two way approach to disability research has been labelled by DFID as a ‘twin...
track’ approach (DFID 2000) – and it is particularly relevant in the field of water and sanitation. Among the specific recommendations based on this literature search and analysis, we offer the following:

- research to better understand the social, economic and public health implications of lack of access to adequate water and sanitation facilities for persons with disabilities;
- increasing the evidence base on experiences of persons with disabilities in accessing water and sanitation facilities, as well as providing concrete examples of what works to improve access;
- cost-benefit analysis and other economic studies documenting the benefits to persons with disabilities, their households and their communities when improved water and sanitation facilities are made available – or the costs when such access is unavailable. Such research would help justify the costs that may be attendant in making current and/or future resources and facilities accessible.

In summary, evidence is needed to lobby at all levels to consider persons with disabilities when adapting existing or constructing new water and sanitation projects. Attention to accessibility of facilities in schools and other public buildings, to facilitate greater inclusion of persons with disabilities in education and employment, are particularly important and consistently overlooked.

CONCLUSION

In order to meet Millennium Development Goal 7 for water and sanitation, as well as to ensure compliance with the new United Nations Convention on the Rights of Persons with Disabilities, access to clean water and basic sanitation must be considered not only a ‘right’ but also a necessary component in all WASH policy and programming. Eliminating water-borne/water-washed diseases within communities and breaking the links between poverty, poor water and sanitation is likely to be impossible unless persons with disabilities are included in all WASH-related efforts.

It is important to emphasise that most persons with disabilities in all communities can be served by low-cost, low-tech innovations or through simple adaptations already documented and readily available online (WEDC; Source 2011). Even less costly is inclusion of basic elements of universal design – ramps instead of steps for example – before new WASH facilities are built. While water and sanitation designs may vary, and there are a range of adaptations needed for persons with different types of disabilities, these differences are limited in number, already well documented and can be easily anticipated and budgeted for. The key is awareness and sensitivity to the needs of this missing 10% of the population.

Finally, WASH experts and advocates do not have to work alone. Consultation and collaboration with DPOs and NGOs that work on behalf of disabled populations now exist in all countries, and can provide expertise, insight and partnerships with WASH professionals at all levels.

Inclusion of disability issues is needed at all levels – from prominent discussion at global meetings to planning sessions at the community level. The inclusion of persons with disabilities is a human right, an economic imperative and an act of enlightened self-interest on the part of civil society, health organisations and governments. Policy makers as well as WASH professionals and advocates would be wise to take notice.

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