

Why should the water and sanitation sector consider disabled people?



Figure 2.1. A typical back-breaking communal shallow well in Uganda.

This chapter is mainly for readers who have had little previous contact with disabled people and disability issues, and limited experience of including disability in their work. This is likely to include water and sanitation (WATSAN) sector professionals, community development workers and public health workers.

2.1 Disabled people are a part of every community

Disabled people are a part of every community, everywhere in the world. They are among the poorest, most marginalised and disadvantaged, and are often hidden. Sadly, disabled people have the least access to basic WATSAN services, which contributes to their continued isolation, poor health and poverty.

The aim of infrastructure and development, including WATSAN programmes, is to improve the well-being of everyone in a community, whether they are male or female, rich or poor, young or old, disabled or non-disabled. It follows therefore that all WATSAN programmes and activities are relevant to disabled people, so a disability perspective should always be included. For example, WATSAN activities targeted at poor people must consider poor disabled people, those targeting poor women must consider poor disabled women, and so on.

Increasingly, WATSAN service providers are recognising that in order to reduce poverty, there is a need to target the poorest, most disadvantaged and vulnerable sections of the population, to provide more equitable access to basic services. This must therefore include disabled people.

2.2 Inclusive facilities bring benefits for all

Improved access to water and sanitation facilities brings a range of benefits to disabled people and their families, including:

- Increased dignity and self-reliance for disabled people. Being able to carry out an activity independently, where they previously relied on others for support.
- Improved health and nutrition.
- Reduced poverty and improved well-being: disabled people and their families save time and effort, which releases time for other activities, such as income generation, household chores, or schooling.

Every community is made up of a variety of individuals with a wide range of needs. Women have different needs and concerns from men, elderly people have different needs from children, and so on. In the same way, disabled women, children and men have a range of needs, many of which are similar to those of other women, children and men.

All over the world, the traditional approach to service provision is to divide people and their needs into 'normal' and 'special', with so-called 'normal' services for the majority of the population, with 'special' facilities or services for disabled people sometimes as an added extra. These 'normal' services rarely consider the reality of the wide range of human needs, with the result that many people in the community are unable to or have difficulty using them.

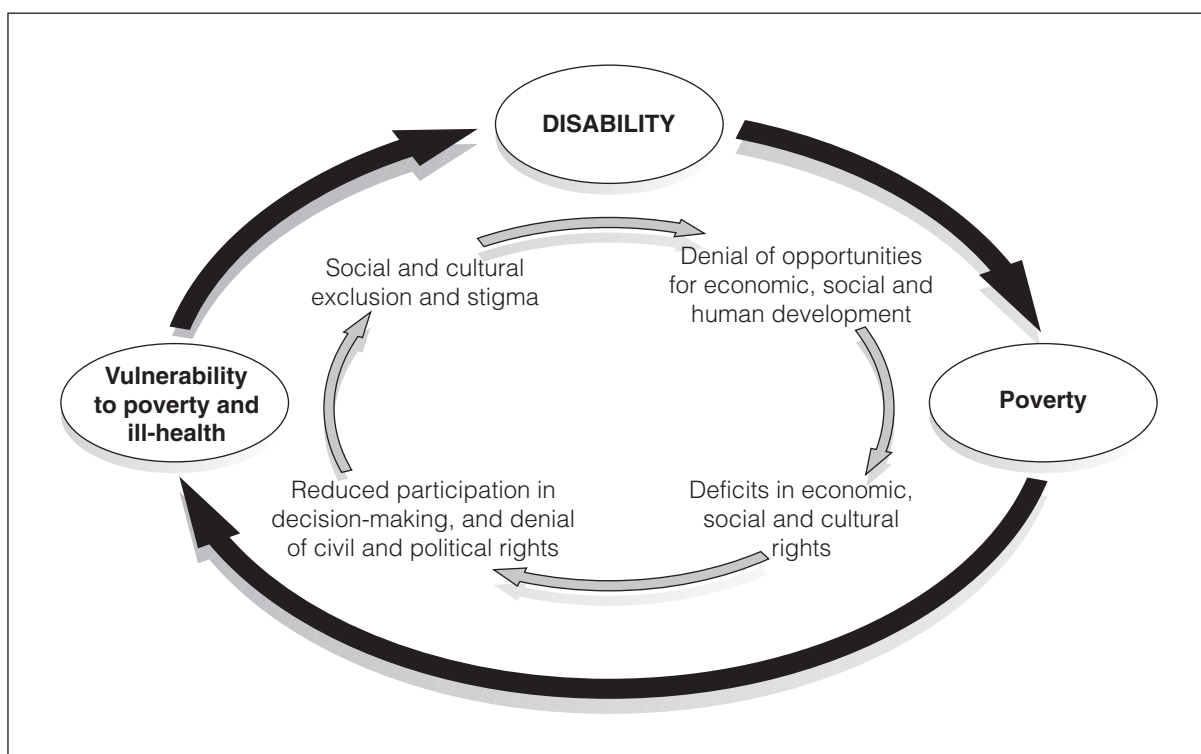


Figure 2.2. Poverty and disability – a vicious cycle (1).



Figure 2.3. Carrying water uphill.

The majority of disabled people do not need ‘special’ facilities – their needs can be met by ordinary services with a little extra thought, and only minor adjustments. Making WATSAN facilities and services inclusive would therefore benefit the whole community. These might include frail elderly people, pregnant women, girls, parents with small children, and people who are injured or sick, including people with HIV/AIDS. Any of these people may have difficulty with their balance or co-ordination, with weak grip, limited flexibility, squatting or lifting, most of which are needed to access WATSAN facilities. Because of this they are likely to experience many of the same problems of exclusion as many disabled people, although they are not described in this way.

2.3 Disability is a poverty issue

Poverty is not only about low income, but also about limited opportunities, choices and social exclusion, all of which particularly apply to disabled people (2). Poverty is both a cause and a consequence of disability (Figure 2.2):

- Poor people are more likely to be disabled. Why? Poor nutrition, bad water, inadequate living conditions, poor hygiene and sanitation, limited health services, environmental pollution, war, conflict and disaster, lack of information, HIV/AIDS, and hazardous working conditions are all causes of impairment.
- Disabled people are more likely to be poor. Why? Inadequate treatment to reduce impairments, lack of suitable equipment such as crutches, lack of access to education or employment, isolation, discrimination. Disabled people are also at high risk of HIV/AIDS infection, as they lack access to health information and are least able to protect themselves (3).

The impact of disability is felt by the whole family, because of:

- Lost income of family members who support disabled people;
- Reduced health of disabled people, leading to increased costs of treatment and medicines, and increased family workload;
- Reduced health and well-being of the family, increased vulnerability and poverty.

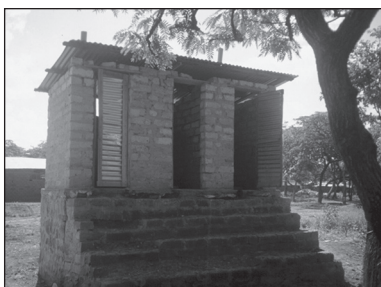


Figure 2.4. Latrine in Tanzania with steep steps and narrow doors.

Lack of clean water and sanitation are key factors in keeping people poor, unhealthy and unable to improve their livelihoods. For disabled poor people, its impact can be doubly difficult. For example, in communities where women go out to defecate at night, moving around in the dark can be extra hazardous for a disabled woman. In many rural areas, diarrhoea is a regular occurrence for everyone, but for a disabled person who needs support, this can place an extra workload on family members.

It is therefore clear that development targets such as the Millennium Development Goals (4) of poverty reduction, improved health, and access to safe water, will never be equitably met unless disabled people are included (5). (See Section 3.4. Millennium Development Goals).

2.4 Inclusive access is good economics

The economic costs of excluding disabled people far outweigh the costs of including them. The costs of exclusion are borne not only by the family, but also by the whole community, in terms of the lost economic and social contribution by the disabled person and their family to the community. On the service delivery side, the creation of 'special', often separate services and facilities is costly, and often a lack of funds means that only a small minority of disabled people benefit.

An inclusive approach to facilities and services is more cost-effective. If inclusion is planned from the beginning, the additional cost is minimal – often as little as 0.2 per cent (6, 7). Even where inclusion has not been planned from the outset, and existing facilities need to be adapted to make them more inclusive, this does not need to be highly technical or expensive.

2.5 Access to water and sanitation is a human right

'Access to safe water is a fundamental human need and therefore a basic right.' Kofi Annan (8)

'We ... confirm our unswerving commitment to water, sanitation and hygiene as human rights and as vital components of sustainable human development.' (9)



Figure 2.5. Steps to the toilet.

The right to safe water is enshrined in Article 25 of the UN Declaration of Human Rights (10), and in Article 27 of the UN Convention on the Rights of the Child (11). A UN Convention on Disabled People's Rights is also currently under discussion, in which the current draft, Article 23 specifically mentions 'Access to clean water' as part of an adequate standard of living (12).

For the majority of disabled people in low-income communities, their human rights to life, food, water and shelter are a daily struggle. The only way they will access these basic needs and rights, and thus an acceptable quality of life, is through inclusion in mainstream services and programmes.

2.6 I'm an engineer, not a disability 'specialist' – what can I do?

As we have pointed out, disabled people have the same needs and rights as everyone else: to adequate living conditions, including sanitation and safe water, access to education and health services, decent roads and transport. The majority of people, including frail elderly people, parents with small children and disabled people, could get their basic needs met and their livelihoods improved through mainstream services and programmes, if a disability perspective was part of the usual way of looking at service provision.

Disabled people do not expect more or better facilities than other people, only to be included, so that they can have equal access. Equity, equal access, and equality of opportunity do not mean that everyone must be treated exactly the same. In order to access their same basic needs, some people may need something a bit different. For example, for a person with difficulty walking to have equal access to water (in other words, spend the same amount of time fetching water as her neighbours), the water point needs to be nearer to her home than to those of her neighbours. Services need to be flexible enough to be able to provide a range of options.

Some disabled people have healthcare needs, and require certain equipment to support them. However, for this individual support to be provided, but without accessible services being available, is often of little or no use to the disabled person concerned (Figure 2.6).

It is not possible for a mainstream WATSAN service to meet the individual needs and demands of all. Some needs are too challenging and beyond the scope of the public health engineer. But not all disabled people need a 'special' service.

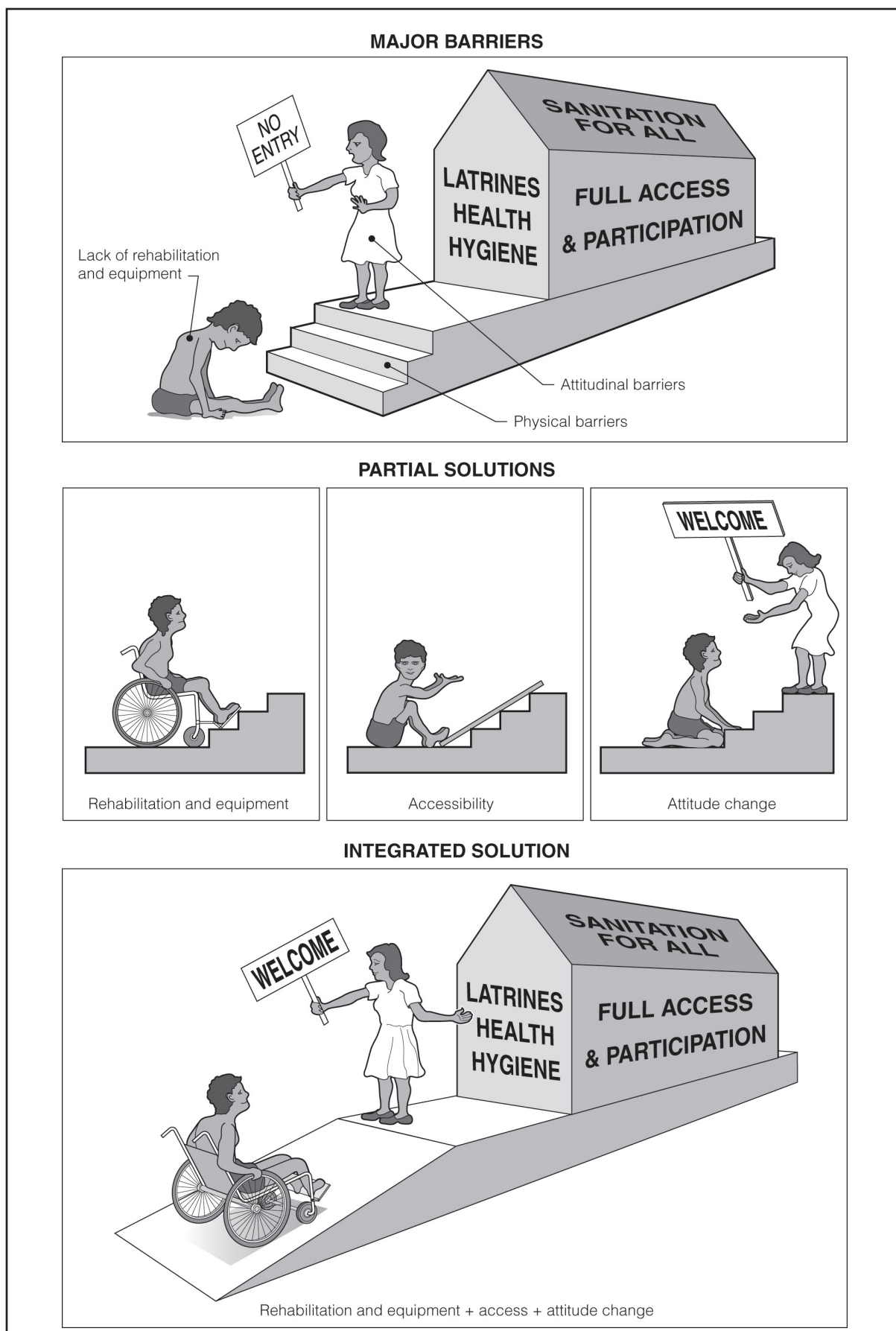


Figure 2.6. Holistic approach to including disabled people (adapted from Werner, 1987).



Figure 2.7. Many rural roads are a challenge for wheelchair users.

A little extra information, awareness and thought on the part of service providers can make the difference between a disabled person being included or excluded by a service.

This means that service providers cannot simply pass responsibility for disabled people to ‘specialists’. Doing nothing is not acceptable. All service providers need to consider ways to ensure that disabled people are not excluded from their services and programmes.

Whilst engineers have design knowledge and skills, they are not always aware of the needs of disabled people. Disabled people, on the other hand, whilst not generally knowledgeable about engineering (although there are disabled engineers) do understand their own access needs. So, when planners and engineers start the process of designing a WATSAN project, they should consult local disabled people’s organisations (DPOs), including disabled women’s sections, to get their input.

2.7 Disabled people are only a small minority, we have to think of the majority first

There are more than 500 million disabled people in the world according to UN estimates. Approximately 80 per cent live in low-income countries (12, 13). Estimates vary from 4 to 10 per cent of the population (14), although a recent survey in Bangladesh found 14 per cent were disabled (15). These numbers are increasing, because of factors such as violent conflict, accidents, HIV/AIDS, environmental pollution and ageing populations. In low-income countries the proportion of older people is predicted to rise from 8 to 19 per cent by 2050 (16).

However, among the poorest of the poor in low-income countries, as many as 1 in 5 are likely to be disabled (17). This means that almost every chronically poor family is affected in some way by disability.

2.8 We don’t discriminate – everyone is included

The WATSAN sector is developing strategies and approaches to understand and respond to the different perspectives and needs of communities, as part of the process of planning and project design. Unfortunately, without intending to, the service delivery process often excludes many disabled people, so their concerns and needs remain hidden.

Sometimes exclusion is deliberate, direct and explicit; for example, by specifying certain groups that are not allowed to participate. But most exclusion is indirect, and arises through a lack of awareness or thought (see Box 2.1). For example, holding meetings in locations where only men are allowed will exclude women. In the same way, holding a meeting on the second floor of a building with no lift or ramp will exclude people who have difficulty walking. Social factors can also lead to exclusion. Where it is the norm for powerless groups such as women, elderly women, disabled people and people of low caste to only speak when asked a direct question, their participation in a meeting will be limited.

The effect of exclusion is the same whether or not exclusion is intended. All the more reason why including a disability perspective has to become the accepted way of thinking about benefiting the whole community, because this is the best way to make buildings and services more accessible for everyone.

Box 2.1. Indirect exclusion

An HIV/AIDS education and awareness project aimed at teenagers and young people in Indonesia welcomed all young people without exception – or so they thought. The organisers admitted that of 5,000 young people using the service in the past year, they knew of not one who was a disabled person. On further questioning, it turned out that the main route to young people, using posters, outreach workers and peer counsellors, was through secondary schools. When it was pointed out that no disabled young people attended mainstream secondary schools in that province, the organisers recognised that they had to find alternative ways to reach disabled young people, such as through a local vocational training centre. *(Author's own experience)*

Box 2.2. Hazardous facilities

A 60 year-old man with physical impairment had a simple toilet of bamboo pieces placed over a ditch. The toilet was very old, and could not protect his privacy. But he could not afford to mend it, so he only used the toilet at night. One night he went to the toilet. When he sat on the bamboo it broke, and he fell into the ditch full of stinky, dirty refuse. No one heard him shouting for help. He was only discovered the next morning, when a person saw some hair of the old man in the ditch. He had died in the night (18).



Figure 2.8. Hanging latrine in Bangladesh – a challenge for all but the very agile.

2.9 So how do disabled people manage?

Some disabled people manage, some do not. Some develop their own solutions, by using and adapting local materials to make equipment that suits them. Others receive support from disability services, which may provide special equipment and advice. However, because water and sanitation are personal private issues, these solutions are often not shared with others who could benefit, so most disabled people must search for solutions in isolation.

Many disabled people do not find solutions, and are forced to use unhygienic practices, like defecating in the bushes, waiting to use the latrine at night (Box 2.2), or using unclean water sources, all of which are damaging to their health and that of their family.

Box 2.3. No more cleaning bed-pans

Mr Mofizuddin could not get into the family's old pit latrine in his wheelchair, so he had to use a bed-pan. His wife had to empty and clean it every day, which she found dirty and unpleasant. Now a local DPO has provided the family with their own latrine, designed so that Mr Mofizuddin can use it independently. The whole family likes using the latrine: it is light, well ventilated, and there is no bad smell, which makes it pleasant to use. But best of all for his wife, the smooth concrete finish makes it easy to keep clean. It is less work and much more pleasant than emptying and cleaning a bed-pan. (*Case-study 9.2, page 161*)

Box 2.4. Reducing a mother's workload

Mrs Kabiito has four disabled children who are unable to walk or speak. She is a teacher, and leaves them each day in the care of their sister, playing and crawling around the family compound. During the day, they urinate and defecate in their shorts. When she comes home from work, Mrs Kabiito has the task of washing all four children and their shorts.

Now Mrs Kabiito has been given a commode stool, which she is gradually training her children to use. She puts the stool with a container under it in a convenient place, so she can keep an eye on the child and continue with other jobs at the same time. As the children gradually learn to defecate into the container, instead of their shorts, she has less clothes washing to do, and already her workload has begun to reduce (19).



Figure 2.9. A family latrine in Uganda.

Family support – a gender dimension

In many communities, particularly where traditional family ties are strong, families consider it their duty and responsibility to support each other. This includes support to disabled people and frail elderly relatives, young children and people who are sick. For the family, this support can become a problem when the workload becomes heavy. Finding ways to make support tasks easier, more pleasant, quicker and more hygienic is helpful to the whole family.

There is an important gender dimension to improving access. Improvements for the disabled person often bring improvements for women and children, since support tasks frequently fall most heavily on them (Box 2.3). Support is often provided by a child in the family (usually a girl) who is likely to be taken out of school as a result (Box 2.4).

2.10 Why didn't we know?

Firstly, the right questions were probably not asked, because personal hygiene issues are not subjects for public discussion in most cultures. Most people are unaware that alternative options are possible and so don't raise the issue. And thirdly, many disabled people are isolated and hidden because of misunderstanding and ignorance in their community (see Section 4.3).

Disabled people are not present: many people find it difficult to move far from their home to access services or attend meetings, including people with difficulty moving, frail elderly people and blind people, among others. Family members who provide support to a disabled person, usually women, may be unable to leave them unattended to come to the meeting on their behalf, and they may be too difficult to carry.

Keeping it in the family: traditionally, it is the family's responsibility to support a disabled member, so they may feel guilty about raising the problems, for fear of being accused of avoiding their responsibility.

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