

Why should the water and sanitation sector consider disabled people?

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List of abbreviations

- DPO disabled people’s organisation
- MDGs Millennium Development Goals
- WATSAN water and sanitation
- HIV/AIDS Human Immunodeficiency Virus / Acquired Immunodeficiency Syndrome
- UN United Nations

1. Disability is a poverty issue

1.1 Disabled people are a part of every community

There over 500 million disabled people in the world according to UN estimates, of whom 3 out of 4 live in low-income countries [1]. These numbers are increasing, because of factors such as violent conflict, accidents, HIV/AIDS, environmental pollution and ageing populations. In low-income countries, for example, the proportion of older people is predicted to more than double by the year 2050 [4].

1.2 Disability and poverty are inextricably linked

Among the poorest of the poor in low-income countries the numbers of disabled people are even higher – as many as 1 in 5 are likely to be disabled [5]. This means that almost every chronically poor family is affected in some way by disability.

Poverty is both a cause and a consequence of disability (Figure 1):

- 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 all contribute to poverty. Disabled people are also at high risk of HIV infection, as they have least access to health information and the tools to protect themselves.

Poverty is not only about low income, but also about limited opportunities, choices and social exclusion, all of which particularly apply to disabled people [7].

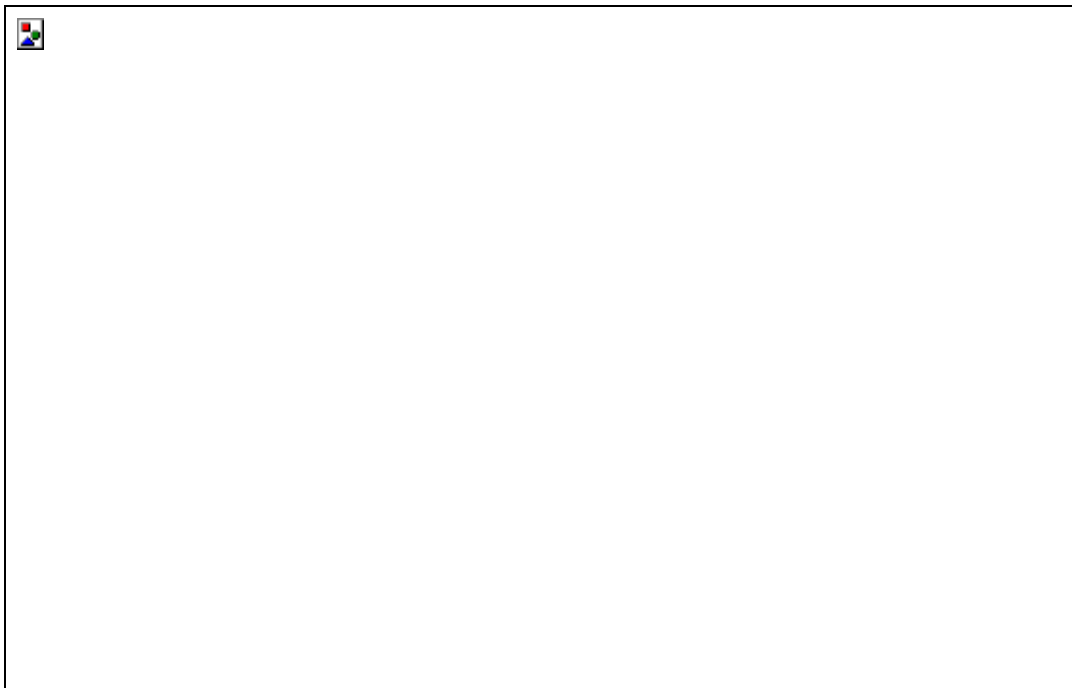


Figure 1. Poverty and disability – a vicious cycle [source 6]

The impact of disability is usually 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 whole family, which increases their vulnerability and poverty.

Lack of clean water and sanitation are key factors in keeping people poor, unhealthy and unable to improve their livelihoods. Sadly, disabled people have the least access to basic water and sanitation (WATSAN) services, which contributes to their continued isolation, poor health and poverty.

For disabled poor people, a lack of accessible sanitation facilities can have a double impact. 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 (MDGs) of poverty reduction, improved health, and access to safe water, will never be equitably met unless disabled people are included [8].

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.

Box 1: 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. *(Account from CRP in Bangladesh) [Jones & Reed]*

2. Disabled people remain forgotten

2.1 How do disabled people manage?

Some disabled people manage with inaccessible facilities, others don't. Some develop their own solutions, by using and adapting local materials to make equipment that suits them. Others receive support from disability services, in the form of individual 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 and their families are on their own in their search for solutions.

Many disabled people don't find solutions, and are forced to rely heavily on their families, or use unhygienic practices, like defecating in the bushes, waiting to use the latrine at night, or using unclean water sources, all of which are damaging to their health and that of their family.

2.2 Why didn't we know?

There are a number of reasons for this lack of information about the situation of disabled people.

- WATSAN planners and implementers do not ask. There is a widespread, but mistaken, belief that disabled people can only be helped by ‘specialists’, and that there is nothing that ordinary people and mainstream services can do.
- Many disabled people are isolated and hidden because of fear, misunderstanding and ignorance in their community, so they are easily forgotten.
- 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.
- Most people are unaware that accessible options are possible, so do not know to offer them, or ask about them.

Box 2. NGO discovers why there’s no demand

A representative of the NGO Forum for Drinking Water and Sanitation in Bangladesh attended a meeting where the issue of WATSAN for disabled people was discussed. As the organisation’s research officer, he realised that his organisation had no information about disability in the communities where it worked. He saw an opportunity to do something about this. The following month a community baseline survey was planned for a new WATSAN programme. It was not difficult to add several questions about disability in the survey.

The results from the survey helped the NGO Forum start to think more clearly what it needed to do about the issue of disability. A significant result was the finding that disabled people and their families do not demand accessible facilities because they are unaware that the possibility exists. Messages about accessibility and its benefits are therefore essential, as well as the hardware. [Jones & Reed]

3. Who do we mean by disabled people?

3.1 The social model of disability

Disabled people are people who have an **impairment**. An **impairment** is a loss or limitation of functioning, whether physical, sensory (vision or hearing), intellectual (learning and understanding) or mental health. People who have impairments are **disabled** by external factors, which reduce their opportunities to participate in family and community activities, on an equal basis with others. These external factors may be barriers in the physical environment, or to do with social exclusion and discrimination. This view of disability is called the **social model of disability**, because it sees society as a whole as responsible for disability.

This contrasts with the traditional medical way of thinking about disability, in which the disabled person is seen as the problem, for which the solution is to provide treatment and therapy, before he or she can fit into ‘normal’ society.

Many people who have impairments may choose not to identify themselves as disabled – elderly people, or people living with HIV/AIDS for example. But as they become frailer, they may experience similar limitations to disabled people.

Box 3: Disabled by the environment

Rita has weak legs, which cannot support her weight - a **physical impairment**.

This means she cannot walk, and moves around by shuffling using her hands – **activity limitation**.

It is the external factors, however, that **disable** her most: the fact that she has no wheelchair, the path to the latrine is muddy, and her family don't like her using the same latrine as the rest of the family, because she crawls and makes it dirty. So she uses the bushes, but because of a lack of privacy she always waits until dark, so her health suffers. [10]

3.2 Barriers and obstacles faced by disabled people

It is not always possible to do anything about the individual impairment of a disabled person. However, most problems for disabled people in accessing WATSAN facilities are caused by external factors, such as barriers in the natural environment or the physical infrastructure, institutional or organisational factors, or social barriers. Examples of different external factors are detailed in Table 1.

It is often very possible to make changes in the external environment. This is where the **knowledge and skills of the engineer are indispensable.**

Table 1: Examples of obstacles faced by disabled people

External factors	Examples
Barriers in the natural environment:	unmade, steep, or flooded roads and paths; muddy and slippery banks of ponds and rivers; water sources too far away, non-existent sanitation.
Physical infrastructure:	high concrete platforms; steps; narrow entrances, slippery floors, handles too high, too low, too heavy, high well walls, containers without handles, etc.
Institutional factors:	WATSAN policies and strategies that do not mention disabled people, community WATSAN consultation without representation of disabled people's concerns, lack of staff knowledge, information or skills on disability issues; disability seen as a 'specialist' or welfare issue.
Social barriers:	Lack of knowledge and understanding, negative behaviour of family and community; prejudice, pity, overprotection; isolation. The whole family may be ostracised or isolated for having a disabled family member, so the family may hide them at home. For example, disabled and elderly people may be prevented from sharing family or community facilities, for fear that they will contaminate water, or make a facility dirty for other people.

4. Why addressing the issue of disability?

4.1 Access to water and sanitation are human rights

“Access to safe water is a fundamental human need and therefore a basic right” Kofi Annan [11]

The right to safe water is enshrined in Article 25 of the UN Declaration of Human Rights, and in Article 27 of the UN Convention on the Rights of the Child. A UN Convention on Disabled People’s Rights is also currently under discussion, in which Article 23 specifically mentions ‘Access to clean water’ [1].

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. For the majority of disabled people in low-income communities, accessing their basic needs and rights is a daily struggle.

4.2 Inclusive facilities are easier for everyone in the community to use

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, disabled children and disabled men have a range of needs, many of which are similar to other women, children and men.

The usual 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, and ‘special’ facilities or services for disabled people sometimes provided as an added extra. However, most disabled people do not need ‘special’ facilities – the majority could get their basic needs met and their livelihoods improved through mainstream services and programmes, if an inclusive design /disability perspective was part of the usual way of planning and designing service provision.

The usual ‘normal’ services rarely consider the wide diversity of human capacities and needs in the community. All kinds of people, including frail elderly people, pregnant women, girls, parents with small children, and people who are injured or sick, including people with AIDS, may have difficulty with their balance or co-ordination, with weak grip, limited flexibility, squatting or lifting, which will affect how easily they can access and use 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.

Designing WATSAN facilities and services to be inclusive would therefore benefit the whole community. This would involve a little extra consideration and awareness, and often only minor adjustments.

4.3 Inclusive access is good economics

The economic costs of excluding disabled people far outweigh the costs of including them. Traditional ‘special’ services and facilities tend to be costly, which usually means that only a small minority of disabled people benefit. The costs of exclusion are borne not only by the family, but by the whole community, in terms of the lost economic and social contribution by the disabled person and their family to the community.

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% [9]. Even where inclusion has not been planned from the outset, and existing facilities need to be adapted to make them more inclusive, adaptations do not need to be highly technical or expensive.

4.4 Disability is a gender issue

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 cause problems when the workload becomes heavy. Finding ways to make support tasks easier, pleasanter, quicker and more hygienic is therefore helpful to the whole family.

Improvements for the disabled person often bring improvements for women and children, since support tasks frequently fall most heavily on them (Box 4, Box 5). 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 5, Box 6).

Box 4. 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. [10]

Box 5. 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 [10].

Box 6: Reducing the workload of children.

Before their treadle pump was installed, it used to take Mrs Noun a whole morning to fetch 4 buckets of water from the river. Because she is blind, one of her children always had to guide her there and back. Now she can draw water without a child to guide her, all the children can go to school, and they have free time to play. [10]

5. Inclusion and equal access in practice

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 the service delivery process often excludes many disabled people, so their concerns and needs remain hidden.

5.1 Exclusion is often unintended

Exclusion can be 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. For example, holding meetings in locations where only men are allowed, automatically excludes women. In the same way, holding a meeting on the second floor of a building, with no lift or ramp, excludes people who have difficulty walking. Social factors can also lead to exclusion. For example, where it is the norm for powerless groups, such as women, disabled people and people of low caste, to only speak when asked a direct question, their participation in a meeting is likely to be limited.

The effect of exclusion is the same, whether it is intended or not. All the more reason why including a disability perspective/inclusive design 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.

5.2 Equal access does not = identical treatment

Disabled people do not expect more or better facilities than other people, only to be included, so that they can have equal access, and equal opportunity to participate in family and community life. However, equal access and equality of opportunity do not mean that everyone must be treated exactly the same. In fact, in order to access their same basic needs, some people may need something a bit different or extra. For example, for a person with difficulty walking to have equal access to water (in other words, spend a similar 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 designed to be able to provide a flexible range of options to accommodate a range of needs.

Some disabled people have healthcare needs, and require certain equipment to support them to access WATSAN facilities – a wheelchair for example. However, to provide this individual support, but without accessible services being available, is often of little or no use to the disabled person concerned (Figure 2).

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

It is not possible for a mainstream WATSAN service to meet the individual needs and demands of all (but isn't that true anyway?) Some needs are too challenging and beyond the scope of the public health engineer. But not all disabled people need a 'special' service. 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, do understand what their access needs are, but because they are not generally knowledgeable about engineering (although there are disabled engineers), they tend to be unaware of what solutions may be possible. So, when planners and engineers start the process of designing a WATSAN project, they should consult local disabled people's organisations, including disabled women's sections, to get their input.

Conclusion

The case for WATSAN services to address the issue of disability cannot be ignored for much longer. The knowledge and skills of the water and sanitation sector will play an indispensable part in making changes in the physical environment, and in service delivery approaches, to provide more inclusive access to disabled people and other vulnerable groups.

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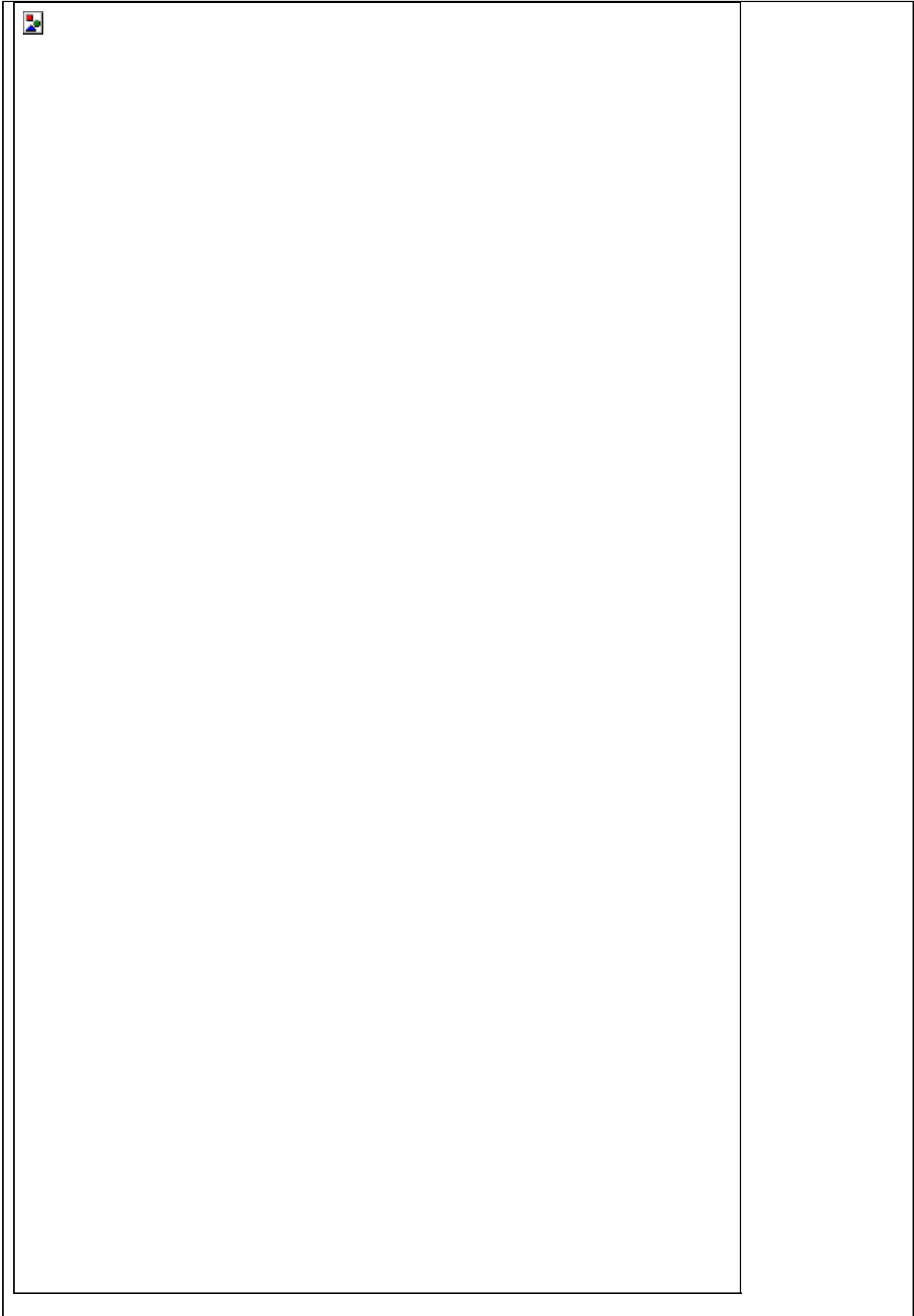


Figure 2. A holistic approach to improving access (source [14])