Chapter 4

Understanding the disability sector

This chapter is mainly for readers who have had little previous contact with disabled people and disability issues, including WATSAN sector professionals, engineers, public health workers and community development workers.

4.1 Who's who in the disability sector

A range of agencies are involved in the disability sector, but can be divided into two main groups – disabled people's organisations (DPOs) and disability service providers. It is important to recognise the difference, as they have fundamentally different views, experience and interests and different roles to play in the development of WATSAN for disabled people.

Disabled people's organisations
These are organisations OF disabled people, run BY and FOR disabled people themselves. Disabled people control and make the decisions, although they may employ non-disabled people within their organisation.

Some organisations are for people with the same impairments, such as physical impairments only, or visual impairments only. Others have cross-impairment membership, which means that they include members with all types of impairment.

DPOs generally focus on advocacy for rights and access to services, creating networks of local disabled people's groups, and capacity building of members to promote their rights. Their projects are based on the priorities of members, such as savings and credit, or income generation. Some DPOs provide services to their members, and a few provide services to the wider community, including non-disabled people.

Many DPOs have a women's wing or committee; some DPOs are run by and for disabled women themselves.

For the WATSAN sector: any consultation with the disability sector should start wherever possible with DPOs, and wherever possible with disabled women in their own right.

This is because DPOs are in the best position to represent the views of their disabled members.

Disability service providers
These are agencies, whether government departments or NGOs, that provide services FOR disabled people, usually run by non-disabled professionals. Services may be provided either in institutions, such as a hospital or residential centre, or in the community, often called 'community-based rehabilitation' (CBR). Sometimes a combination of both approaches is used.

Some organisations have a medical focus, such as operations or physiotherapy, some provide charitable handouts, whilst others focus on education or social issues, such as attitudes and behaviour of communities.

For the WATSAN sector: When identifying relevant agencies to consult on WATSAN issues, those with a more social or community focus are likely to have more relevant experience to offer, and are more likely to be interested in collaboration.

4.2 Who do we mean by disabled people?

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 (Box 4.1). This view of disability is called the **social model of disability**, because it sees society as a whole as responsible for disability.

For example, 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**.

What **disables** her most, however, are the external factors: the fact that she has no wheelchair, the latrine is too far away, the path 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 always waits until dark, so her health suffers.

Box 4.1. Disabled by poverty and inaccessible toilets

Daniel is 15 and has weak legs – **a physical impairment**.

He has difficulty moving around – **activity limitation**, but he wears calipers and uses crutches, which help.

He is **disabled** by his poor quality calipers, which often break, and by poverty - there is never the money to repair them. So he often has to crawl around, which makes his hands dirty. His father refuses to eat with him because of this.

He is **disabled** by inaccessible toilets, both at home and at school, which he cannot get into with his crutches. At home, his mother gives him her plastic shoes to wear on his hands, to protect them when he crawls in. At school, however, he says he never uses the toilets because he has nothing to wear on his hands there, and there is urine all over the toilet floor. (1)

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 to enable him to 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 more frail, they may experience similar limitations to disabled people. Many of the ideas in this book will therefore be helpful for them.

4.3 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, and social barriers. Examples of different external factors are detailed in Table 4.1.

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 4.1. 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.

4.4 Approaches to addressing disability

Different strategies and programmes address the issue of disability in different ways. They fall broadly into the following types:

Disability-focused projects/services

These provide services or interventions which focus on disabled people, such as mobility aids, operations, physiotherapy, artificial limbs, vocational training, capacity building. They may be stand-alone or a sub-component of a wider programme, e.g. Primary education programme + Project on education for disabled children with learning difficulties.

As with projects that focus on women, disability-focused projects are appropriate under certain conditions. The risk is that they increase the isolation of disabled people, if they are seen as an end in themselves, rather than as a necessary basis for improving social inclusion.

Including a disability perspective
Also called 'integration' or 'mainstreaming', this is where the project/ programme recognises that disability, elderly infirmity, and ill-health are experienced by all communities, and explicitly considers and responds to this diversity and range of needs in its service provision. There is no expectation that disabled people should be 'cured' or 'rehabilitated' first before they can be included.

Twin-track approach
This recognises that 'including a disability perspective' and 'disability-focused projects' are both needed (2). Disability-focused projects aim to maximise the skills and abilities of disabled people, which are an essential prerequisite to enabling them to access inclusive services.

Prevention of impairments/disability prevention
Examples of strategies for prevention of impairments include immunisation to prevent polio, Vitamin A to prevent night blindness, and accident prevention campaigns. These are necessary components of any public health programme, but cannot be considered as development approaches to disability, as they do not benefit disabled people who are part of every community.

For the WATSAN sector: The key approach is the second, i.e. including a disability perspective. This means that every WATSAN project, programme and service should consider the needs of disabled people from the beginning and throughout, as the usual way of doing things. This is the most important contribution that the WATSAN sector can make, and is an essential component of a twin-track approach to disability.

4.5 Different approaches to problem-solving

Disability organisations often use approaches to solve issues of disabled and other vulnerable people that are different from the approaches that most engineers are used to. The disability sector tends to focus on the needs of individual disabled people and their families, rather than on whole communities, so the focus is usually at an individual household level, rather than a community level.

A meeting between the disabled person and their family and relevant community/ health workers is a common approach to problem-solving. The purpose should ideally be to listen to what the disabled person has to say, and how they see

Box 4.2. Not the perfect solution – Maya and her family

Maya is a 22-year-old wheelchair user, living with her family in a rural area of Bangladesh. Her arms and legs are stiff and she needs help with many everyday tasks, which is the responsibility of her sister-in-law.

The family is poor, and as there was no latrine, they all used the surrounding fields to defecate. This was impossible for Maya, who would squat behind the house, and her sister-in-law swept the faeces into the bushes.

An NGO provided the family with a brick-built latrine, with a concrete ramp that was accessible for Maya's wheelchair. The idea was that the whole family, including Maya, would benefit from using the sanitary latrine.

A few years later, this had not happened. An older brother had got married and built his house in front of the latrine, so it was no longer possible to get into it in a wheelchair. And anyway the toilet was blocked. The family had gone back to defecating in the fields, and Maya was squatting behind the house. It was not clear whether the house came first or the toilet was blocked first.

The solution had appeared fine in theory, but what was the practical reality? Even at first, Maya needed her sister-in-law's help to use the latrine. It was a distance from the house, up a slope, so she needed her to push her wheelchair. She needed help to move from wheelchair to the toilet. The toilet seat was narrow so her sister-in-law had to stay with her while she used the toilet, otherwise she might fall off. For the sister-in-law, this took up a lot of time and effort, and increased her workload. It was quicker and easier to let Maya squat behind the house.

The failure of the solution provided indicates that one solution does not fit all. It is important to consider the disabled person not in isolation but in the context of the family. The views of the sister-in-law and her workload needed to be considered. It did not consider alternative solutions that would enable Maya to do more for herself, rather than rely more on others. (4)

the solution to the difficulties they face. It is common to find several different opinions on the causes and solutions to a problem, and to negotiate the solution that most suits the disabled person. Any solution imposed by an 'expert' is likely to meet resistance or lack of interest, if it is not seen as achieving the desired outcome (Box 4.2).

For the WATSAN sector: The engineer can be a valuable resource, by:

- Providing information about possible options (where the disabled person has no opinion);
- Working out the strengths and weaknesses of different solutions; and
- Helping to turn an idea into reality.

Engineers need to be

ON TAP

NOT ON TOP (3)

The final choices and decisions should still be made by the disabled person and their family.

Issues of difference

Disabled people are women, men and children, of all ages, with different impairments, needs, lifestyles and views. They may be doubly marginalised for other reasons, e.g. disabled elderly people, disabled people from ethnic minority communities, disabled girls, disabled people living with HIV/AIDS. One solution does not suit all. For example, an ex-soldier with an amputated leg is unlikely to have the same concerns and needs as a mother with a disabled child, and it should not be assumed that he can represent her views. It is therefore important to consult, not only articulate men with a physical impairment, but also those who are rarely consulted – poor disabled women, people with communication difficulties, people unable to leave the house, and their family carers.

4.6 Introduction to working with disabled people

The majority of DPOs in low-income countries have formed only within the last ten to twenty years. For many, their main struggle is to make their voices heard, and to be granted the same human rights as everyone else, instead of being seen as objects of pity and charity.

Because of this, some disabled people may not be immediately convinced that it is worth spending time discussing the issue of WATSAN, and that it will lead to practical results. Most disabled people have not reached the stage of systematically working out practical solutions to the problems of access and inclusion.

This does not mean that they don't have ideas and solutions; they do, but they may find it difficult to explain the issues in a way that engineers can immediately relate to. It may take a while to develop trust and an understanding of how to work together.

Meeting disabled people

Non-disabled people do not always understand the practical difficulties that disabled people face. We may not recognise how our own behaviour can enable or disable, help or hinder someone who is different and may have an impairment. Understanding our own reactions and behaviour towards people who are different may take some time. Basic common sense, and courtesy that we normally show other people, can do a lot to help overcome barriers. Just act as you would with anyone else and be open and honest.

For a list of further resources on working with disabled people, see Appendix A1.6 on page 262.

The following advice may also help. It does not include the full range of impairments, which is why the first point is particularly important.

- Everyone is unique. Try not to make assumptions about a person's capacity or needs. Listen to what they have to say and respect what they tell you.
- Try not to make assumptions about who is and is not disabled as some impairments are hidden, e.g. diabetes.
- Offer help, but be careful not to take over. Don't be upset if help is rejected. Sometimes it will be welcome, but sometimes it won't be needed, or may hinder the person doing an activity in his or her own, maybe slower, way.
- Speak directly to the disabled person, not at or to their helper or interpreter.
- Look at the disabled person, not at their impairment, or the wheelchair/trolley.
- When talking to a wheelchair/trolley user, try to sit down at a similar height, or stand with a suitable space to allow direct eye contact. It can be very exhausting having to look up all the time. Don't lean on the chair, you may tip it over! This can also be intimidating and an invasion of personal space.
- When communicating with a person with a speech impairment, give them time to express themselves, concentrate and don't be afraid to ask for something to be repeated if you don't understand an answer.
- Disabled people often have a lack of self-esteem and confidence – be encouraging and sensitive to their needs. Be patient, show trust and respect confidentiality.
- When communicating with someone who is deaf or has a hearing impairment, find out how they choose to communicate. If they lip read, face the person and speak slowly and clearly, with the light on your face. Don't shout or cover your mouth. Be patient because lip reading involves a high level of concentration and it can be exhausting.
- You may need to use an interpreter, particularly if someone uses a sign language or communication system you do not understand.

- When talking to a blind or visually impaired person, make sure they know who you are – they may not recognise your voice. And remember to say when you are leaving them, so that they do not end up speaking to the air.
- When talking to people with difficulty understanding, speak simply, using short words and sentences.
- Find out more from national level DPOs who can provide locally appropriate information and advice.

Language

The language we use when describing or speaking to other people can convey respect or disrespect. This is the same for disabled people. Words that seem straightforward at first glance may have a negative or offensive meaning for disabled people. They may be acceptable in one language or country, but unacceptable when translated into another language. Users should also be aware of who decides whether a term is acceptable: a word used by a doctor, for example, may not be acceptable to disabled people, or parents with a disabled child.

Table 4.2 contains some guidelines reproduced from materials that reflect current thinking in the UK. These are for guidance only, they are not exhaustive and are likely to change over time. They will need to be adapted for use in other languages. If in doubt, ask disabled people which words they find acceptable, and reject words that they find unacceptable.

This book also frequently refers to disabled adults and children, disabled girls and boys, or women and men with disabilities, to keep in focus the gender and age differences of disabled people.

Table 4.2. Appropriate language

Avoid	Use
Cripple, defective Invalid *(this literally means 'not valid')* Retarded, subnormal	Disabled person, disabled child Person who uses/walks with crutches Person with an impairment or Children with disabilities, people with disabilities
Handicapped *This is derived from 'cap in hand' and implies begging, which reinforces negative stereotypes.*	
'The disabled', 'The blind', 'The deaf', etc. Phrases like these are dehumanising.	Disabled people Blind people, people with visual impairments Deaf people, people with hearing impairments
An epileptic, a cleft lip girl, a CP case, etc. It is offensive to label people with their impairment.	Person with epilepsy Girl with a cleft lip Person with cerebral palsy (CP)
Victim of … Crippled by … Suffering from … Afflicted by....	Person who has … Person with … Person who experienced …
Wheelchair bound Confined to a wheelchair	Wheelchair user, wheelchair rider *For many disabled people, a wheelchair is a liberation, not a confinement.*
Normal and abnormal: describing people who are not disabled as 'normal', implies that disabled people are abnormal. In fact disabled people are a normal part of every society. Sick: implies that disabled people are all unhealthy. Everyone is sick from time to time. For example, a woman with difficulty walking as a result of polio may fall sick with diarrhoea like anyone else, but having weak legs does not mean that she is sick.	Non-disabled people and disabled people

References

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