

# **Water supply and sanitation access and use by physically disabled people**

**e-conference synthesis report**

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## Glossary

ADL	Activities of daily living
BPKS	Bangladesh Protibandhi Kallyan Somity
BNBC	Bangladesh National Building Code
CBR	Community-based rehabilitation
CRP	Centre for the Rehabilitation of the Paralyzed, Bangladesh
DFID	Department for International Development
DPO	Disabled people's organisation
FIM	Functional Impairment Measurement
GO	Governmental organisation
HITS	Uganda Society of Hidden Talents
ICIDH-2	Second draft of <i>The International Classification of Impairment Disability and Handicap</i> . The full reference of this finalised document is: WHO (2001) <i>The International Classification of Functioning, Disability and Health</i> . World Health Organisation: Geneva.
NGO	Non-governmental organisation
OT	Occupational therapist
PWD	People with disabilities
UN	United Nations
UDPDC	Upazilla Disabled People's Development Council (Bangladesh)
WEDC	The Water, Engineering and Development Centre

## Introduction

The Disability, Water and Sanitation e-conference was held in September and October 2002. It forms part of Phase One of an Engineering Knowledge and Research (EngKAR) project, R8059, entitled 'Water Supply and Sanitation Access and Use by Physically Disabled People'. This research is funded by the UK Department for International Development (DFID) and is being carried out by WEDC at Loughborough University, UK.

*The purpose of the project is:*

To improve the knowledge and use of affordable aids, methodologies and structures, by organisations and individuals who assist physically disabled people and their families living in low income communities, to maximise their access to and use of the domestic water cycle.

The aim of this e-conference was to provide a forum for sharing information, experiences and views on issues related to disabled people's access and use of water and sanitation facilities. This synthesis report documents the conference proceedings and contributes to WEDC's ongoing research on access to water and sanitation for disabled people (for more information see <http://www.lboro.ac.uk/wedc/projects/auwsfpdp/index.htm>).

The conference was conducted using the Disability Water and Sanitation (DWS) jiscmail email discussion list<sup>1</sup> ([dws@jiscmail.ac.uk](mailto:dws@jiscmail.ac.uk)) during September and October 2002. The e-conference was publicised widely via web sites (e.g., WEDC, IRC, The Water Page, GARNET) and emails to principle contacts involved in work with disabled people and provision of water and sanitation facilities. During the conference, 40 members were subscribed to the list, among them representatives from international development agencies, disabled people's organisations (DPOs), and academic institutions. The list members were located in more than 17 different countries, across all the continents. Of these 40 people, 15 participated in the conference, posting over 40 messages to the list. All relevant contributions are included in the report.

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<sup>1</sup> The DWS email discussion list is for exchange of views and information on issues relating to disability, water supply and sanitation in low-income communities. After the conclusion of the e-conference, DWS reverts to an un-moderated list, still linked to the project, and monitored by staff at WEDC.

It is worth noting however that contributions listed as sent by Muhammad Mushfiqal Wara, were from not one person, but at least eight!

The conference was divided into three discussion themes:

**Theme 1:** Barriers to accessible water and sanitation facilities (9-22 September).

**Theme 2:** Strategies to improve access to water and sanitation facilities – examples of good practice (23-29 September).

**Theme 3:** Tools to support improved access to water and sanitation facilities – strategies for the future (30 September - 4 October).

Each theme began with an introductory paper, two of which were written by disabled people from low-income countries, the other by the WEDC conference facilitator. The discussion was then open for any contributions on issues relevant to the theme. This report consists of a summary of key issues raised by contributors and conclusions drawn from these. There is then a set of appendices containing contributions and papers submitted during the e-conference and a list of the contributors. We have only presented in the report the contributions that are directly relevant to the three themes. Omitted contributions can be found, unedited, in the archives for the e-conference. The contributions presented have been copy-edited. Also, inevitably, the content of contributions does not always fit neatly within the themes under which they were submitted, and so this report has re-categorised some contributions.

Where appropriate, the name of the contributor and the date (day/month) of the relevant contribution are provided in brackets. Archives of the DWS discussion list can be accessed at <http://www.jiscmail.ac.uk/lists/DWS.html> E-conference messages can be found under September and October 2002, and have the prefix DWS1, DWS2, or DWS3 for each of the themes.

# 1. Summary of key issues

There were three themes for this e-conference:

- Barriers to accessible water and sanitation facilities.
- Strategies to improve access to water and sanitation facilities (examples of good practice).
- Tools to support improved access to water and sanitation facilities (strategies for the future).

Below is a summary of the contributions (full contributions can be found in Appendices 1-4). While on the whole there were a lot of contributions discussing barriers and looking at suggested future steps, there were not as many contributions providing examples of tools and approaches that have actually been used.

## **Barriers to accessible water and sanitation facilities**

The contributions to the e-conference highlighted a wide range of barriers, for both disabled people and service providers.

### ***Toilet facilities***

This issue elicited the most information from participants. A common problem is the fact that the buildings or rooms housing the toilets/latrines are inaccessible — either because the rooms are too small to accommodate wheelchairs or because the floor level changes. Many structures are also old, badly made and generally unsafe for users, especially disabled users. They may also fail to protect users' privacy, which was raised as a particular concern for disabled women.

The squat toilet/latrine is hard for disabled people to use, especially when there are no handles to use for support or to help them stand up. For blind people in particular there is the risk of stepping in the hole. Due to mobility difficulties, disabled people are more likely to come into physical contact with toilets/latrines or floors, and so poor levels of cleanliness or very wet conditions make using the toilet unpleasant. In places where wet toilets/bathrooms are common (e.g., Asia) there are specific problems for disabled users — wet and slippery conditions can be dangerous and the required removal/changing of shoes before entering or leaving the wet room can be difficult.

Disabled users often experience difficulty cleaning or washing after using the toilet, especially if they have limited or no hand function. This problem can be compounded if they also have to carry water to the toilet for washing or for flushing, because no water is stored in, or piped to, the toilet.

### ***Washing/bathing***

Personal bathing and washing utensils or clothes from water stored in tubs or buckets is hard for users who cannot scoop water with their hands, or lift a bucket. One contributor raised the issue that for disabled women this difficulty with maintaining cleanliness becomes worse during menstruation. Showers are generally not available in low income households, so splash-bathing is the most common. The distance to the bathing place and difficulties with carrying water to these places, create barriers for disabled users. For blind users, showers can also be problematic if they are not familiar with how to operate the shower.

### ***Sources of water and storage of water***

A wide range of water sources was identified by participants, all of which can be inaccessible to disabled users. For example, any type of source may be too far away to be reached easily by disabled users. The condition of the terrain surrounding tanks and wells may be rough, and there are often steep and slippery approaches to rivers, canals and springs. Such terrain is difficult and dangerous for physically and visually impaired users. River water in particular can be deep and frightening to users with limited mobility or vision. The height and design of pump handles and the design of lifting mechanisms in wells may not accommodate disabled users.

Carrying water can be hard for disabled people as appropriately designed or adapted vessels may not exist. Water is commonly stored in traditional storage pots (often large and heavy) which may be placed off the ground for ease of pouring. Handling such pots may not be possible for users with limited/no hand function or those who cannot lift objects. A further problem highlighted was the lack of knowledge among disabled users about how to safely store and purify water for drinking.

### ***Barriers within the community***

Several participants commented that the negative attitudes of other community members towards disabled people, hinders their access to and use of water and sanitation facilities. Not only are other people ignorant about their needs, but they may even ridicule or abuse disabled users. Disabled people may be considered low priority users — left at the back of the queue, especially if there are water shortages. There is often an assumption (by professionals) that families provide the help that disabled people need regarding water and sanitation. Often, however, disabled people are managing alone, or their family members/carers do not have the necessary knowledge or skills to help them ensure better access. When it comes to involving disabled people in decision-making or planning processes, there may not be existing or effective systems in the community for consulting disabled (or non-disabled) community members.

### ***Barriers at the national and governmental level***

Priority is not given to disabled people's needs and rights generally in most societies. Most countries lack the legislation relating to disability rights that could bring access issues to the wider attention. Alternatively, where legislation does exist it is not being well implemented. An example from South Africa showed that in government housing schemes for low income households, even when the planners had been briefed about the needs of disabled people, they continued to ignore this and create inaccessible toilets/bathrooms.

### ***Socio-economic issues***

Participants commented that disabled people cannot afford accessible facilities and assistive devices, or it is assumed that these will be expensive because local cheap alternatives have not been considered. In some cases disabled people do not have enough land or space in their home for introducing sanitation facilities. In low income communities a lack of electricity or gas (or a lack of money to pay for them) also prevents disabled people from boiling/purifying drinking water.

### ***Professionals, service providers, engineers***

Many of the contributions stressed that there is a lack of (or poor access to) context- and culture-specific information and guidelines for engineers/designers. They also lack accurate information on the cost of accessible design (leading to an assumption that it is high cost).

Professionals can create barriers — some participants hinted at the inflexibility of engineers and their resistance to change or to implement what they learn in training. There can be a fear of tackling an unknown area, perhaps linked to the fact that many engineers, etc, are required to have little direct contact with user groups (disabled or non-disabled). Several participants described water and sanitation professionals as having the wrong attitude to disability and not being client-focussed.

The role rehabilitation professionals can play in assessing disabled people's water/sanitation needs and advising both the user and provider was raised, but it was stressed that there are just not enough occupational therapists (and similar) available.

### **Strategies to improve access to water and sanitation facilities (examples of good practice)**

There were not many concrete examples of good or improving practice offered during this e-conference, which reflects the situation highlighted in the initial research conducted by WEDC.

### ***Local solutions***

One key example came from Uganda, where a local organisation for disabled people (HITS) has researched, designed and developed a range of tools and gadgets to help disabled people make use of water and sanitation facilities. The tools are made from affordable local materials and include an armchair latrine seat, a toothbrush stand for people with no hand/arm function, knee protectors made from old tyres (to protect users when crawling in latrines/bathrooms) and a wheelchair carrier for carrying water. Although a lack of resources means that these developments have not been widely produced or distributed, HITS sees already their potential advantages to disabled people and to the community. For example, disabled people can access water and sanitation facilities more easily and carry out tasks more quickly and with less as-

sistance. This not only promotes the idea of independent living, but leaves more time for disabled people and their carers to take part in other developmental activities.

BPKS in Bangladesh also noted during the e-conference that they have taken steps to ensure accessible tube well and sanitary facilities for rural disabled people, children and pregnant women, with assistance from One Family International. Their innovative and cost-effective approaches are being adopted in other countries. However, BPKS did not provide any further information on the details of their initiatives.

### ***Guidance for professionals/engineers***

In Bangladesh a detailed set of guidelines about accessible environments has been produced by CRP, for use by OTs, engineers, builders and other professionals (and which disabled people can also use for information). While not exclusively about water and sanitation, the guidelines cover these issues in some detail; outlining the basic considerations for planning bathrooms, toilets, sinks, kitchens, etc, and providing details of ideal features and measurements. CRP have disseminated the guidelines through government and professional organisations, and have run workshops, where professionals have shown interest in the idea of creating accessible facilities. The local government engineering department is subsequently implementing recommendations from the guidelines in their engineering work plan.

### ***Assessment***

CRP have been assessing levels of access and integration (for example by including water/sanitation issues in a study of inclusion of people with spinal cord injury). This will lead to the development of a questionnaire to obtain information from disabled people using OT services, about what they really need to help them access facilities. CRP hopes that the study could be a reference point for future studies on integration and water/sanitation (as currently most OTs do not assess water/sanitation needs and abilities).

### **Tools to support improved access (strategies for the future)**

The guidance questions for this theme stressed 'what can this project contribute to support people and organisations wanting to improve ac-

cess?’ Inevitably, suggestions have been offered that go beyond the scope of this project. All suggested strategies have been summarised below.

### ***Information***

Most of the suggested strategies focused around the issue of information.

The general feeling from participants was that there needs to be more information available, provided in more suitable formats for use by a wider range of users, not just professionals. However, we also need to explore different ways of *collecting* information from disabled people and professionals, to get a balanced picture of needs and appropriate responses. The need to find ways of reaching people who could not be reached by this type of e-conference was highlighted.

We need to develop ways of providing information that suits both literate and oral communities and which uses different media (e.g., drama) to inform people about access rights, needs and options. Visually impaired users also need access to information in Braille or on audio-cassette regarding what facilities are available or how to use them.

Strategies and methods for disseminating information are needed. It was pointed out that current dissemination methods through NGO networks miss out so many small groups or individuals not in the network. One suggestion was for the creation of voluntary information centres or representatives, to help filter information to those who need it, which includes disabled people (information flows often currently stop at the level of local service providers).

Following on from this research project, it was suggested that there could be community discussions or workshops to share the project findings. DPOs/self-help groups could arrange these and use the workshops as a starting point for community surveys of the situation and solutions, (with community awareness-raising being a by-product).

Several participants discussed the possibility of developing (through WEDC) a guidance document. This could contain key principles and detailed practical information, aimed at engineers, architects, planners, DPOs and other stakeholders. There was some debate whether the document should cover countries in the North and South, as some

countries nominally in the North (e.g., those in east and central Europe) would also benefit from improved water and sanitation initiatives. It was suggested that a guidance document should include photos, simple drawings and simple language/short text (using David Werner's publications such as 'Disabled Village Children' as an example of a suitable style).

### ***Participation of disabled people***

Another issue raised by most participants was the need to develop better ways of involving disabled people in water and sanitation initiatives, at all stages — assessment, planning, design, information dissemination, etc — to ensure that solutions actually suit users.

In particular the need for gathering information from disabled users was stressed, as research/documents contain very little from this point of view. It was also suggested that we could build on the potential role that self-help groups/DPOs have of bridging the gap between disabled community members and professionals/service providers. One participant stated that it should be a requirement for all technical professionals to meet regularly with DPOs in the area in which they work. Disabled people should also play a central role in evaluations of programmes.

### ***Rehabilitation***

The role of rehabilitation was emphasised in a few contributions — i.e., ensuring that disabled people's basic need for rehabilitation is met first, if that is what they need in order to use water/sanitation facilities. As there are not enough OTs, etc, it was suggested that we need to do more work to help family members, traditional healers, etc, learn how to assist disabled people or how to teach disabled people basic skills (including using water/sanitation facilities).

### ***Changes in approaches***

The overarching need to mainstream disability was raised in the Theme 3 discussion paper, stressing that it is everyone's responsibility, not just an individual problem. There needs to be a move towards all sectors co-operating to bring about accessibility. We also need to work more on

coming up with context/culturally appropriate or adaptable designs and solutions.

It was suggested that we should move away from our reliance on architects or engineers (we assume they are needed if we want accessible environments), and instead inform and train the already skilled local labourers to build accessible water and sanitation facilities (through on-the-job training).

One participant highlighted the need for a change in approach by NGOs and service providers, as some seem to be motivated by selling their local innovations and making money, rather than really assisting disabled people with access. There was also a suggestion to turn more attention to alternative water sources, such as developing rainwater collection and purification methods that disabled people can use in their own home.

### ***Government and international community***

The need for some international standards was highlighted (e.g., a standard way of labelling a hot tap). There should also be lobbying of governments to get them involved, and more work on raising awareness among governments, community leaders, the media, etc.

### **The e-conference process**

A couple of participants made comments relating to the nature and process of this (or any) e-conference. Muhammad Mushfiqul Wara commented that most e-conference participants seemed to be professionals, and there was a need for more input from disabled people and their organisations, as well as women with disabilities. (DSW1[18] – 16/9/02).

Donatilla Kanimba was concerned by the lack of contributions from people with sensory impairments. Blind people in particular she felt would not be aware of this conference, and they and their organisations would not have access to e-mail or modified facilities (DSW03[06] – 4/10/02). Muhammad Mushfiqul Wara added that this lack of access to e-mail was widely applicable to many NGOs and networks (DSW3[08] – 7/10/02).

## 2. Conclusions

This e-conference — to which 40 people subscribed and in which 15 participated — has reinforced some of the initial research findings of WEDC. It has added useful insights regarding the social and physical barriers that disabled people face in accessing water and sanitation facilities. Participants were also able to offer suggestions for future initiatives. The e-conference, however, did not add significantly to the pool of knowledge about examples of good or improving practice in accessible service and facility provision.

### Key conclusions/recommendations

There is a lack of toilet and washing facilities in low-income communities, and those that are available are inappropriately designed and constructed for disabled users, or are dangerous. There is a need for the creation and/or wider dissemination of guidance documents (such as those highlighted during the e-conference) which promote and advise on the development of locally appropriate facilities.

Disabled people do not have suitable ways of collecting and safely storing water. There need to be more water supply sources created or adapted for use by people with physical and sensory impairments. There is also a need for developing water vessels suited to disabled users and awareness/training work, among disabled users, on water purification methods.

Attitudes among community members, engineers, architects, NGO/government/international policy/decision-makers and other professionals can prevent or inhibit disabled people from gaining access to and using facilities, so awareness raising/training about disability, accessibility and disabled people's rights has to continue among all groups. There is a need to break away from 'doing what has always been done'.

The general belief that achieving accessibility requires high levels of technical expertise and funding needs to be challenged. The economic situation of communities and disabled people means that 'imported' solutions to accessibility are often too expensive, so there needs to be more effort invested in further developing the kind of cheap, locally appropriate solutions offered by some of the e-conference participants.

The availability and sharing of knowledge and information is one of the most significant problems. There is a need for information to be gathered from all stakeholders, to ensure that the problems and solutions identified are truly representative. Information needs to be made more available, using a wider range of formats to suit different users (not just professionals). More effective use of existing networks, DPOs, community consultation mechanisms, etc, should be explored as a way of gaining and sharing knowledge. A simple guidance document could be produced by WEDC.

The participation of disabled people is still minimal in many assessment, planning, implementation and evaluation processes, so there is a need to continue and strengthen efforts/mechanisms for including disabled people.

As an overarching recommendation, disability and accessibility issues need to be taken on board by everyone involved in water and sanitation work, there needs to be a recognition that it is everyone's responsibility, in every sector, at all stages.

# Appendix 1.

## Disability, water and sanitation — introductory paper

*Hazel Jones, Research Associate, WEDC*

This introductory paper is designed to provide an overview of the issues to be covered during the e-conference, and to clarify what the conference hopes to achieve.

Disabled people are among the poorest of the poor, and often the most marginalised when it comes to accessing basic services and facilities, a situation which is compounded by discrimination and social exclusion. Despite this, the majority of development and infrastructure programmes fail to consider the needs of disabled people. An increasing number of governments, non-governmental organisations (NGOs), donors and international organisations are now recognising that an effective disability strategy has to include addressing the needs of disabled people in all mainstream development programmes. Few people would disagree with this in theory, but how should it actually be implemented in practice?

An early overview of the literature in this area (Jackson, 2000) indicated that there was a lack of information about access for disabled people to water and sanitation facilities. A more in-depth review, currently nearing completion at WEDC, confirms that very little written information, either published or unpublished, seems to be available. It appears that most disabled people are left to manage as best they can, with inconvenient and even inaccessible facilities. Examples of good practice — technologies and approaches that really make a positive difference for disabled people — have been hard to find, and where they do exist, they tend to be isolated examples. It is likely that there is a wealth of practical experience at family and community level, but which remains undocumented and not shared with others, because most people are too busy to communicate their experiences.

### **What does the conference hope to achieve?**

The main purpose of this e-conference is to remedy some of these information gaps, by drawing on the practical experience and knowledge of conference participants. In order to maintain a focus, and to enable in-depth discussions to develop, the conference will be divided into three week-long themes:

Barriers to accessible water and sanitation facilities.

Strategies to improve accessibility – examples of good practice.

Tools to support improvements in access – strategies for the future.

Firstly we hope to explore the barriers to access and use of water and sanitation facilities for disabled people, identify the most significant barriers, and the stages in project/service implementation at which they occur and analyse their causes. We will then move on to share practical experience of addressing these barriers, and to understand the factors contributing to success or failure in overcoming them. The aim of the final week of the conference is to clarify what this research project could usefully contribute to support people and organisations in their work of improving access to water and sanitation facilities. This might include identifying potential target audiences, the kind of 'tools' needed to support improvements, appropriate formats, and effective dissemination strategies.

### **References**

Jackson, Clare M (2000) 'Domestic water supply and sanitation facilities for the physically disabled living in low-income rural and urban communities of developing countries. A review of the literature'. For WEDC, Loughborough University, UK. Available on <http://www.lboro.ac.uk/wedc/projects/auwsfpdp/index.htm>

## Appendix 2.

### Theme 1 — Barriers to accessible water and sanitation facilities

#### Introduction

The first theme began with a discussion paper, written by Inge Komardjaja, a disabled woman from Indonesia, which highlighted some of her personal experiences, (DWS1[01] - 5/9).

#### *Discussion paper*

Presently the needs of disabled people are not a concern for the Indonesian government, since poverty alleviation is their priority concern. The institute where I work [Research Institute for Human Settlement] has very little understanding about barrier-free design of buildings. Before, I only paid attention to concepts that aim at independent mobility and I had never thought about a connection between disabled people and water and sanitation facilities. The topic of this e-conference intrigues me.

This paper is about people with a disability that affects their legs and/or arms. They may be ambulant or non-ambulant (e.g. wheelchair user).

#### **Barriers**

##### *The wet bathroom and toilet*

Instead of squatting, disabled people may sit on a very low seat or on the floor, when washing clothes or when the walls of the open splash-bathing tank are low. [In Asian-style splash-bathing, the bather stands next to large water container/tank, and scoops water from the tank over his/her own body - HJ]. Standing up is a problem if one's arms are impaired because they are not strong enough to lift up the body.

Using the wet squatting toilet is hazardous for disabled women. [In Asia, the toilet is often situated in a bathroom with a shower/splash-bathing area, which means the floor is always wet - HJ]. They have to half-bow and half-squat while holding the door handle or the edge of the open tank when they want to urinate. Some do not drink prior to travelling, to avoid having to use a public toilet, which for disabled men may not be so troublesome as they remain standing when urinating. Once I travelled and had the urgent need to use a public toilet. As it smelled of urine I cleaned it by pouring water on the surroundings of the hole and afterwards sat above the hole on the floor. Agitatedly, I tried to stand up by kneeling and holding the water pipe to lift myself from the floor, but I slipped several times. Eventually, I stood up with bruises

on my legs and my clothes wet. My disabled woman friend could not use a public toilet as the room was too narrow to accommodate her wheelchair. She had to refrain from urinating until she arrived home.

People also squat on the flap of a sitting toilet and use plenty of water to clean themselves, making it dirty and wet. In such circumstances I have to clean it, first by pouring water and then putting the flap up to drain excessive water. How troublesome this is for people in a wheelchair or with crutches.

In other people's house we are expected to use the wet toilet barefoot. To take off shoes is a real hassle for disabled people, because they have to sit somewhere or stand on one leg. If they don't remove shoes, they may dirty the dry floor. [In Asia, wet/dry, clean/dirty areas are often kept separate by removing shoes, or providing indoor shoes/sandals, or providing sandals specifically for the wet bathroom - HJ.]

#### *Scooping water*

Impairment in arms and hands makes it difficult to scoop water of 1-2 kg and to lift the container up to pour the water over the body when splash-bathing. It is also difficult to scoop water with hands to wash dishes. In my friend's house, the bucket containing water was on the ground; people had to squat and scoop water with their hands to wash the dirty dishes. I felt guilty and useless as I could not help them. Both my hands are impaired, the left hand more seriously. If standing, I will put the dishes on the bottom of the sink and scoop water with my half-able hand.

#### **Attitudes towards disabled people**

Disabled people are not able to use water and sanitation facilities as speedily as the non-disabled. It is unlikely that disabled people will be given priority to use these facilities. A similar example is my experience in using public transport. Some drivers ignore me and won't stop the vehicle as soon as they see my disabled walking.

#### **Human assistance**

Disabled people in low-income communities cannot afford to buy wheelchairs, crutches, walking frames, and other assistive devices. It would be more practical and economical to carry a disabled person if they are not able to crawl or drag themselves. Consequently, they are constantly at the mercy of others and their liberty is robbed. Even if assistive devices become affordable, it is questionable whether, in low-income communities, disabled people are encouraged to be independent in mobility.

## Concluding remarks

There is very little understanding about disability, and occasionally even a lack of sympathy for disabled people. Although creating barrier-free public buildings and spaces is important, the provision of accessible water and sanitation facilities is more urgent, and should be mandatory, because the day-to-day human biological needs cannot be delayed.

## Guidance questions

### *User level*

- What other barriers do users face in using domestic water and sanitation facilities, which have not been raised here?

### *Organisational level*

- Are disabled people explicitly considered among the target beneficiaries of services?
- Do policies and strategies exist, that aim to address the needs for access and usability by disabled people or other marginalised groups? If not, what are the reasons for this?

### *Service provider's perspective (e.g., planners, managers, technical personnel, community workers)*

- What are the problems or obstacles that arise when trying to deliver inclusive services?
- At what stage in service delivery/project cycle do the problems arise, and what are their causes?

## Contributions

The submissions relevant to this theme are presented here in a slightly edited form. Some of the shorter contributions have been grouped according to common issues raised.

### ***Service providers' perspective***

*The conference facilitator, Hazel Jones started the discussion by conveying two points raised by an engineer colleague, (DWS1[02] - 11/9).*

Firstly the colleague felt that even if he was asked to build accessible facilities, he would face a lack of information on how to go about it.

He has also seen, in his own experience of working to mainstream gender is-

sues in water and sanitation, that many engineers do not change the way they work, even when they have had 'gender' training/sensitisation. They continue to work from the same standard designs they have always used, without considering the diverse needs of the people who will use them. He commented that

'Many consider that "gender" means having a couple of women on the water committee, and that's it, without recognising their own responsibility to reflect on and maybe adapt the way they work'.

*Inge Komardjaja added to the points relating to gender and standard design (DWS1[01] - 12/9):*

I am interested in the gender issue. In my institute, gender is also understood as [being about] women, not both women and men. Water is considered a need for women in low income communities, because of the household chores. Later professionals admitted that men and children also need water, so they labelled water as a family issue. But the term gender remains related with women. Similar to Mr Reed's experience, in Indonesia people build public toilets with the same standard of design without considering the needs of different able-bodied people, let alone disabled people.

*Hazel Jones then shared the results of a discussion with five engineers, based around the question 'If you were asked to provide water/ sanitation facilities accessible for disabled people, what problems would you face?' (DSW1[05] - 13/9)*

Only one of the five participants had ever been asked to provide access for disabled users (this was for toilets in a school in China).

#### *Issues for engineers*

- Lack of available information: if facilities were for private use, I would find out users' needs. If for public use, there is such a wide range of impairments and needs, I wouldn't know where to start! Guidelines and design specifications exist for the UK, but there is a lack of information and guidelines about solutions for low-income communities. Even when you know information exists, it can be difficult to get hold of. For example, we know of a water and sanitation NGO in South Africa which has guidelines on disabled access, but these are not available on their web site.
- Fear of doing the wrong thing, (this is seen as a specialist issue) so it is safer to do nothing.
- Lack of awareness among engineers, because of the nature of their training, which focuses on objects, rather than people and their needs. In fact, consultation with users about their needs is not the job of the engineer, who normally just receives a design brief from the decision-makers.

- Cost implications — access for disabled people often costs more, but again, there is a lack of information on the costs of accessible designs.

#### *Community context*

- Community attitudes: In rural areas of some countries, there can be a lot of superstition and taboos about disability. From experience in Zambia, for example, the community's expectation was that the government will take care of disabled people by housing them in special institutions, and it was felt that to provide facilities in the community was too expensive.
- Disabled people normally have family members around to help them, so access is not perceived as an issue.
- In South Africa, one colleague encountered intolerance, among the community, of elderly people using public latrines and making a mess.

#### *National context*

- Service provision for the poor in general is low priority for governments; disabled people are a minority group among the poor and so are even lower priority.
- Legislation and policy level — issues of disabled access need to be included.
- There is a lack of information on economic arguments for including the needs of disabled people.

#### *Organisational context*

- There is a need for policy and guidelines on accessibility.
- In many countries, mechanisms for community consultation, e.g., local community/district council, do not exist or do not work.

So to summarise — if engineers only do what people ask them to do, then the problem is that there is no demand — no demand from governments, no demand from water/sanitation programme planners, and no demand from communities or from disabled people. Is this true?

### ***The Bangladesh context***

#### **Context of access and use of domestic water and sanitation facilities for physically impaired people in Bangladesh.**

This paper was prepared by Self-help Group Leaders who are physically impaired and represent the physically impaired people of Tangail, Mymensingh, Gazipur, Narayanganj, and Manikgonj districts of Bangladesh. They participated in a three-day Disability Equality Training organised at the Centre for the Rehabilitation of the Paralysed (CRP), Savar, Dhaka in July 2002. An e-conference co-ordinator has also supported their preparation for this e-conference.

*Contributors:*

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**General situation of disabled people in Bangladesh: experiences of self-help group leaders**

The living conditions of disabled people in the communities are very poor. Since they are ignored within the family, most of them are dependent on begging. The attitude is such because disabled people do not have opportunities to earn a living and they live in conditions where facilities are very scarce.

Participants preparing for this e-conference learned about the problems and hurdles facing their disabled peers. First they felt that disabled people needed treatment and secondly some means of earning their livelihood. They found that women and children with disabilities were especially vulnerable in the society. They observed that children with disabilities are often hidden from relatives and neighbours, especially in some families with higher social status. Disabled people are discouraged from joining in activities.

The participants thought that active participation in this conference would be a very wonderful idea, since the issues of access and use of water and sanitation facilities for physically impaired people are very much neglected, but these are vital for living. An active participation in this conference would mean that the voice of disabled people will be raised and may bring a positive change in the lives of disabled people.

**Physically impaired people in Bangladesh**

This paper reflects both participants' experiences of working with disabled people and their own life experiences. The six districts covered consist of rural and urban settings. However most information reflects rural life experiences, since 85 per cent of people in Bangladesh live in rural communities.

The discussion will involve the access and use of domestic water and sanitation facilities for physically disabled people in Bangladesh. This paper mainly identifies the barriers of access to water and sanitation facilities, by providing some basic information on general sources of water, general use of water; collection, storage; and gender differences in access and use of these facilities (gender issues will be covered later in detail). Barriers faced by disabled people will be highlighted through two unfortunate examples that affected disabled people and the community, due to unavailability of proper sanitation facilities.

## Barriers to access to general sources of water

There is no barrier free water source for physically disabled people. The general sources of water identified are:

- Tube well/deep tube well.
- Tank water.
- Canal or river.
- Tap water.
- Well

Generally, low income people share water from tube wells and tanks. Tube well use is the most common, followed by tank water, canal or river and fourth the well. Tap water is the least used in rural areas and mostly used in urban low income communities, mainly sponsored by municipalities. However, in many places this practice is gradually withering.

The general barrier of all these water sources is that these are placed at a distance that makes it hard for physically disabled people to access them.

### *Tube-well*

- Placed at a distance.
- Swampy place.
- Improper height of tube-well (in most cases higher than useable).
- The design of the pump handle is unsuitable for a disabled person.
- The pump handles are tough to press to lift water.

### *Tank*

- Placed at a distance.
- Absence of platforms in most cases and, where available, platforms are unsuitable, restricting access for people with disabilities.
- Lack of handles for disabled people to hold on to while accessing water and for getting up after fetching it.

### *Canal or river*

- Distance.
- Current.
- Steep edges.
- Depth.

### *Well*

- No suitable mechanism to help disabled people lift water.
- Swampy surroundings.

### *Tap*

- Placed at a distance.
- Inadequate in number.

## **Barriers to collection and storage of water**

Difficulties with the collection of water create a general barrier to the use of water by physically disabled people. Storage of water is mainly in jugs or earthen pots, which are locally made. These pots generally contain a little water and are stored high off the ground, making it easier to pour water from them. Using water from these pots is difficult for disabled people who have problems with their hands due to paralysis. The situation is severe for a person who has both hands paralysed.

## **Barriers in use of water**

Water is used for many purposes including drinking, bathing, washing, cooking, toilet use, and cleaning the household. All these uses of water pose more problems for a physically disabled person than a non-disabled person. The barriers faced in using water in a domestic environment are given below.

### *Drinking*

Disabled people feel that physical lack of hand function is the most painful barrier in drinking water. A disabled person can move to the stored water but cannot drink it, because he or she cannot adequately handle the storage pot. The second barrier is the lack of pure water. Water impurity may be caused by iron and arsenic contamination. Arsenic contamination is a huge problem now in Bangladesh. Inaccessible procedures and a lack of knowledge about how disabled people can purify water, is a barrier to accessing drinking water.

### *Bathing*

Bathing places are often placed at a distance. In the rural areas, the surroundings are generally swampy — they get slippery and there is a risk of falling on such a surface. People who have problems with their hands cannot carry water to the bathing place, even if they have been able to store water in a bucket or pot. There is no provision for having a shower in rural areas, so people with paralysis/limited hand function are often unable to use water for bathing on their own.

### *Toilet/latrine use*

Physically impaired people face a great problem in cleaning themselves after toileting or latrine use. This is severe for persons with limited or no hand function. In most toilets in the rural areas, water is not stored in the toilet and is carried, in a pot, to the toilet by the users. This poses a problem for wheelchair users, since their hands are occupied with the wheelchair.

### *Cooking*

For physically impaired people, cooking is not an easy task. Cooking requires washing and the use of water. If water is stored at a distant place, or at a height from the ground, or on a shelf which is not easily reachable, stored

water cannot be adequately used.

### *Cleaning*

Generally disabled people face problems in cleaning utensils for cooking, and in the use of water for general activities of daily living, (such as washing hands, feet or mouth, and washing clothes) because the sources of water are at a distance, or because water is not easily collectable, or it is not easy to use stored water.

### **Structural barriers in access and use of sanitation facilities**

The toilet as a structure is itself a problem. Persons using crutches cannot use the toilet properly because often there is no handle or support, which they can hold on to while sitting in the toilet. Persons using wheelchairs need adequate space for manoeuvring, which is not often available even in public toilets. Often the floors of toilets are at a higher level making it difficult for a wheelchair user to enter. The current design of toilets does not suit the needs of persons with amputated lower limbs, meaning these people cannot sit in the toilet.

Toilet structures can be dangerous for a physically impaired person. There may be a risk of injury. In the following case the person died.

#### **Box 1**

An old person (about 60 years) with physical impairment used to use the toilet at night. The toilet became old and could not protect the privacy of the person. He could not afford to mend it, so he developed a habit of using this toilet at night.

The night is usually very dark in villages. One evening he went to the toilet. The toilet was a very simple structure. It was a ditch on which some bamboo pieces were placed. The bamboo pieces were old. As soon as he sat on them they broke and he fell down in the stinky, dirty ditch full of refuse. No one could hear him shouting for help. His voice could not reach other people, who could have saved him. A person saw some hair of the old man in the ditch the next morning, he had died in the night.

### **Barriers to hygienic sanitation**

In contemporary Bangladesh many sanitary toilets have been established at many rural holdings. However, still a large number of holdings do not have a safe toilet, or at least have a toilet near home. In urban Dhaka some public toilets have been set up, but at the district level, this facility is not available. The example in Box 2 is certainly not good toileting practice and pollutes the environment.

**Box 2**

At a suburban set-up in Mymensingh, a person with both legs amputated above the knee, used to work as a rickshaw mechanic and he lived at the rickshaw garage. There was no toilet nearby. He had real difficulty in moving, as he did not have any assistive device. He could not use the toilet and so he used to toilet either on some sheets of paper or in a polythene bag at the garage. He would then throw the refuse at an open place.

However the fact should be interpreted that disabled people are sometimes forced to behave in ways that they would not do, if, for example, appropriate public toilet facilities were available, or if at least some appropriate assistive devices were available to them.

**Factors responsible for inadequate service provision of water and sanitation for disabled people in Bangladesh.**

*This contribution from Ehsunul Ambia Suhad and Muhammad Mushfiqul Wara (DWS1[09] - 16/9) reiterates some of the points raised above and introduces some new issues.*

1. In Bangladesh, understanding of general people about the need for appropriate water and sanitation facilities for disabled people is lacking. Obviously many service providers lack knowledge about the specific needs of disabled people in the community. Professional efforts relating to access and use of water and sanitation facilities have not been taken by services providers. However, there is seemingly an NGO forum for water and sanitation in Bangladesh. There is a huge lack of occupational therapists (OT) in Bangladesh. Only a few organisations have qualified OTs, who are coping with the volume of immediate needs in integrating disabled people in the community.
2. Presently OTs have been carrying out assessments in activities of daily living (ADL), which should include the issue of water and sanitation. Within the limited capacity of the OT service, CRP is trying to initiate interventions in this area. Social welfare services collect data on water and sanitation facilities existing at clients' homes on admission. On home visits these are assessed and necessary advice is given. The community-based rehabilitation (CBR) department contacts appropriate service providers in the community to support these people with facilities. Unfortunately, many service providers are not knowledgeable about how to make accessible water and sanitation facilities for disabled people.
3. The economic condition is a big issue in the provision of accessible water and sanitation facilities for disabled people. Usually they cannot afford the cost. Also many of the households in the community do not have adequate

space or land to make an accessible toilet. In many households we have experienced that people take baths on a bamboo platform [seat]. They have to lift water in a bucket to splash bathe. It is not possible for a disabled person to sit on the bamboo, or to lift water. However, there is no space where an accessible bathroom could be established. People cannot afford them. This is the picture in rural households and urban slums.

4. Also many households do not have a supply of electricity or gas, which means they are unable to purify water for drinking. There is a lack of knowledge about how disabled people can purify water without using any kind of power/energy. Service providers have not focused on disability and have failed to support them in these cases.

5. Since the attitude of the community is still negative towards disabled people, special facilities are not strictly considered for them. They are obliged to use the existing facilities in most cases, which are not appropriate for them. Therefore disabled people try to make do with the existing facilities and we have known how dangerous the result can be [see story in Box 1].

6. There is a need to change the way disabled people are perceived by the service providers. The existing service providers need to consider the effect for disabled people. The voices of disabled people need to be considered if we value a client-centred approach.

*Md. Abu Zahid offers some experiences of a person with a paralysed hand, and shares the story of a paralysed young man who is trying to find a solution to the toileting problems he faces. (DWS3[05] – 3/10/02)*

The following is my experience. I am Md. Abu Zahid. I have been working as an Administrative Officer in CRP for the last six months. I have been working as the Co-ordinator of the Self-Help Group of Disabled Persons, Upazilla Disabled People's Development Council (UDPDC) in 61 Upazillas in Bangladesh. This is a new initiative of CRP. We hope that the problem of bringing services to the doors of disabled persons will be addressed through the effectiveness of these groups, which will bring real development to the lives of disabled people of Bangladesh.

I encountered a road traffic accident four years ago. I could never know how the accident happened as I was in a deep sleep. Later I found that I had broken fissure of the right leg and received brachial flexuous injury to my right hand. My right hand from the elbow down became paralysed. Though after an operation upon the fissure I could walk, still the right hand is paralysed.

I was right handed. Slowly I became acquainted with using my left hand, and in the process of trying to do so I felt the following problems.

I was always a 'doing' person. It was a harassment not being able to clean the plate properly after a meal, not being able to pour water in a glass from a jug. I could hardly handle any water source other than 'supply water'. I wanted to hate drinking water outside home!

I could not use water in a 'cost effective' manner, much of the water was wasted, as I could not manage proper splashing over my whole body. Always some part of my body was unreachable by water, and by my soap. I had to finish bathing with little water. I was never satisfied with my cleanliness. Nevertheless I wanted to wash my own clothes. It was difficult for me to rinse the cloth with soap and thrash the cloth with the left hand, which was my only hand.

I did not want to go to any toilet where 'supply water' was not available. It was only possible where supply water was available and I needed much water, and frequent use of water. Moreover I needed sanitary paper after every toilet use.

Now I have developed my skills to do the ADL with my left hand. I have always lived in 'urban' standards. The toilets were good. My problem was primarily adapting to the new limitations. My friends were gone but gradually I have conquered the psychological capabilities.

Shafiqul Islam (15) is a tetraplegic patient whose both hands are not working. He has his mother as a carer. He feels that none but his mother will assist him to her last breath. Shafiqul is very unhappy that his mother has to live with him, leaving her three-year old daughter some hundred miles away.

Shafiqul cannot use his hand now, though he is undergoing hand therapy at CRP. He is practising holding a glass, though he has not yet been able to do it. A patient counsellor informed us that he was developing strengths in his hand. He is very worried that if he is not able to hold things with his hand, he would hardly be able to clean himself.

Shafiqul is currently using a long trolley for mobility. He releases excreta on a plain paper or polythene, which his mother drains into the toilet. Neither he nor his mother knows what kind of toilet he would require. The only knowledge he/his mother has now is that he will be required to use a wheelchair and that it would not be any problem to do toileting in the rear of their home if a shed could be made. They are both sure that he will not be able use the toilet they have now, which is a ditch stationed on some bamboo over pond water covered with some thatch. They hope, provided they have money, that they will set up a toilet, but neither of them knows what a suitable toilet would be like for him. Unfortunately, until now none of the service providers at CRP have informed them or shown them a model toilet, which they could strive to have made at their yard with the help of social workers. Whatever help the social workers would like to provide to them, nothing will happen if they cannot afford

to buy materials necessary for setting it up. It is only a dream for the son and mother, who virtually live hand-to-mouth.

*'Suppose you have a toilet at home, how you will use it?' I asked him. He said, 'For about 150 taka you can buy toilet pan and 2-3 rings to place beneath the toilet pan to set up a toilet. I can get into the toilet, but I should not flush water after toilet, because the ditch will be full. So I will do toilet inside but clean myself outside'. 'But then your toilet will always be stinky' I said. 'Yes, I can drain some water, but it should not be much otherwise it will be full' his mother told me in response.*

*'Can you not use water inside the toilet?' I asked him. He said, 'I could not use water. I cannot use my hands'. 'Some water can be kept inside the toilet in a bucket, that I can help him to clean' his mother added.*

*'Do you keep water in the toilet you have now?' I asked them. His mother said, 'No, we carry water'. He said 'I have been informed that water can be carried with a wheelchair, so if I am in a wheelchair I would be able to carry water to the toilet as well'.*

Shafiqul does not even know how he will be able to keep himself clean without the help of his mother. He has brothers and sisters, but he is not confident about them, saying,

*'They may only help for a few days. I am trying to learn to keep myself clean. I am undergoing hand therapy now at OT'. I asked him, 'Do you brush teeth yourself?' He said, 'No, but I am trying to do it'.*

## **Experiences of women with disabilities — Bangladesh**

*Submitted during Theme 2 (DWS2 [2] - 19/9).*

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- Md. Sahadat Sarwar
- S. M. Mohorom Ali
- Md. Badsha Mia
- M. M. Azhar Hossain
- Hosneara Perveen
- Muhammad Mushfiqul Wara

The contributors of this paper collected data from three different groups of people (women, children with physical impairment, and their carers) through individual interviews at the hospital premises of CRP. The objective of these interviews was to identify issues for women and children with physical impairments, regarding access and use of water and sanitation facilities, and the experiences of carers in assisting these members in accessing and using water and sanitation facilities at their home environment. Interviews were identified as necessary since, so far, experiences of barriers in this area have been

explored from the male population. However some issues have been identified which concern the female population. The gender differences have not yet been elaborately considered. We are still living with the assumptions we have regarding the social roles of women and social attitudes toward them. If the assumptions are true, then in fact women and children will face more barriers than usually felt by their male, (especially adult) counterparts.

In the analysis, some new issues have successfully been explored, which were not considered in our earlier discussion paper on Theme 1.

### **Situation of physically impaired women**

Generally people in Bangladesh, living in the low income groups, have only one toilet and bathroom, which is used commonly by all members of the household. The toilet and bathroom are usually poorly decorated, lack a door, lack electricity, lack a container in the facility (toilet and bathroom), lack adequate ventilation and lack washing materials like soap, towels and/or sanitary napkins. Therefore, use of these facilities by female members is really uncomfortable because they fail to preserve their privacy since these do not have a door or a shed over their head, do not have pure water contained in a pot within the toilet/bathroom, or a sanitary toilet/sanitary napkins. Some of the issues identified above may apply to all people, irrespective of sex and age, disregarding disability. However, issues of disability create experiences for females which do not happen to their non-disabled counterparts.

Therefore, the structural facilities have been identified as the number one problem faced by women in their domestic environment. The second problem is hygiene for women, which is independent of disabilities. Access to and use of proper water and sanitation facilities are a necessity for women, especially during menstruation. Since cleanliness can protect them from being vulnerable during this time, they require pure water for washing, along with proper sanitary napkins. During this period, they require more frequent use of water and sanitation facilities than ever. In low income communities women do not have these necessities due to economic hardship and lack of knowledge — knowledge about disability-friendly water and sanitation facilities, and about hygiene. Their situation is aggravated when common negligence towards women is imposed. Many women are left to use old rags for cleaning during menstruation, which is undoubtedly very unhygienic.

In the urban slums, most slum dwellers have to work outside, both men and women. They are one of the low income earner groups in the society. In some urban slums, the government has developed some water collection facilities, with the help of a funding organisation, but women with disabilities face accessibility problems to reach them, let alone collect the water. Moreover there are no toilet facilities, which are easily usable and protective of their privacy in these slums. In this case, people with disabilities, irrespective of age, face

enormous difficulties; the situation of women is worst.

### **Experience of carers of physically impaired people**

Within the environment of the hospital, carers feel that they have adapted themselves to assist the members in accessing and using water and sanitation facilities at CRP. Since they have not yet returned to the community it seemed unrealistic for them to imagine the exact problems they will face for the disabled members. However, they realised that a home visit, after discharge, would be very useful to identify their problems and to let service providers know their actual situation, so that they could be assisted with modifications of facilities, regarding water and sanitation, in the future.

### **Experiences of carers about children with physical impairments**

To some extent, children are cared for up to a certain age. Children with no physical disabilities start to adapt to their surroundings, especially they learn to use water and toilet facilities. However, children with disabilities will have to be cared for, and in most cases the carers, who are mainly mothers or any female relatives, will face greater difficulties if they do not understand the limitations of their children and how to facilitate them with their shortcomings. Professional interventions were thought to be necessary to help mothers gain these abilities. However, current service providers may start to include some tips for these carers, so that they begin to gain some sort of control over the existing facilities relating to water and sanitation at the home environment.

## ***Sensory impairment***

*Muhammad Mushfiqul Wara (DWS1[06] - 16/9) raised (on behalf of the self-help group leaders) the fact that:*

The physically impaired people [in their group] think that visually impaired people would not face as many barriers as the physically impaired, who have upper limbs or lower limbs paralysed or amputated. These people will face much difficulty. They said that if any blind or visually impaired person is prior informed about the source of water and sanitation, and if things remain unchanged at the said place, they won't face any problems. They also requested to hear the experiences of blind or visually impaired people.

*A contribution submitted during Theme 3 (Kinamba, DWS3[06] - 4/10) provided explanations of the barriers faced by visually impaired people:*

Blind people use white canes when possible, or sighted guides, when travelling in Africa. The white cane, or any cane, becomes almost useless in the rural areas because of rough terrain, especially in the areas close to water

points. As such, many simply try to walk with no alternative aid. This can be very dangerous, as it is not always possible to get the assistance of a sighted guide. Unfortunately water is one of those services which is not always provided by government or NGO.

To come back to problems which can have solutions, I would like to observe that in places like hotels and guest-houses, there is nothing to tell or show a blind person which tap is for cold or hot water. You have to turn on the taps and you wait and feel. You will have been told many times that the left side is hot but it is not always that way. Nothing tells you how to operate the shower, whether you pull, push or turn and of course sometimes you don't even know what a certain knob is for. In toilets, where the toilet is a hole in the floor, blind people are quite often in danger of stepping into the hole.

### ***Accommodating disability needs in planning and policy***

*Meshack Mndawe provided an insight into the barriers facing disabled people in South Africa (DWS1[11] – 16/9):*

Mpumalanga was predominately a rural province in the previous regime of apartheid government. The new South Africa government is in the process of eradicating the imbalance of the past, which was totally isolating people with disabilities. African people in general were having no access to sanitation as they were low income communities, especially disabled people.

We used to fetch water from rivers and springs. Wheelchair users have had difficulty fetching water from the river and bathing in the river. There was a deep stream of water — being Deaf I can bathe as able-bodied persons, but the physically disabled find it difficult to bathe in such streams, for fear of drowning.

The low income housing was created by the new government in an attempt to redress the imbalance of the past neglect of the majority African people. However, the low income housing toilets and bathing rooms are uncomfortable for people with disabilities because of their structure. The housing is very small and the bathing room is inaccessible for people using wheelchairs to enter. They have to crawl, then pick themselves up to the bathroom basin.

The planning and programming personnel were briefed about the issues affecting people with disabilities, but they keep on doing the same thing without accommodating the needs of people with disabilities. They have negative attitudes toward disabled people. Measures were taken in the legislation to act against the discrimination of people with disabilities in terms of service delivery. The equitable standard of practice should be implemented. I call on the world to transform and implement the UN programme of action for people with

disabilities, UN Standard Rules on Equalisation of Opportunities for People with Disabilities, to put it into action not only in declaration papers.

‘Nothing About Us Without Us’ — people with disabilities should be consulted before developing any policy guidelines, programmes of action and in the implementation of these programmes, etc. Without us there will be nothing fit for us. Forward with our participation in global, national, local and community level developments. This will ensure we disabled people spearhead and provide advice and make decisions on issue affecting us.

### ***Barriers for physically disabled people — Uganda***

*Problems encountered by physically disabled people in accessing and using water and sanitation facilities in Uganda, were summarised by Musenyente Elijah (DSW1[12] - 18/9):*

#### *Water*

Steepness to water sources.

- Sympathy/ridicule by others who come to collect water.
- The long distances to where water is collected.
- The type of container used to carry water may be inappropriate.
- Sometimes there is a struggle at the well for one to get water, especially during drought (survival of the fittest).
- The height of the bore hole may be inappropriate, especially for wheelchair users.
- The disabled most times are too poor to make financial contributions, especially for maintenance, and therefore may be denied water.

#### *Sanitation*

- Dirty toilets.
- Steps at toilet entrances.
- Toilet rooms too small for wheelchair users.
- Lack of water and soap after visiting toilet.
- Toilet seats are inappropriate to one's disability

## Appendix 3.

### Theme 2 — Strategies for improving access to water and sanitation (examples of good practice)

#### Introduction

The second theme for this e-conference was introduced with a discussion paper by Musenyente Elijah, Chairman of the Uganda Society for Hidden Talents (HITS).

#### *Discussion paper*

In Uganda the present type of facilities for proper hygiene and sanitation are not suitable for people with disabilities (PWDs). This puts PWDs at risk of contracting diseases related to poor hygiene and sanitation.

Based on experience and considering the nature of different disabilities, HITS, a local NGO for disabled and able bodied in Pallisa District, has been tracking hygiene and sanitation related problems faced by PWDs. Necessity being the mother of invention, HITS has designed and developed local facilities/gadgets for PWD's proper hygiene and sanitation. These facilities are made from local materials, such as timber, and are affordable. Due to limited resources, these facilities are still in a model form. The facilities designed and developed include:

- A model latrine for PWDs.
- An armchair latrine seater for PWDS.
- Ramp access (to be superimposed on stepped access)
- Wooden handles to assist PWD crawling in unhygienic places.
- Adaptable broom to enable PWD to sweep.
- Adaptable dish rack to enable PWD to wash or clean utensils.
- Toothbrush stands for PWD without hands to be able to brush their teeth.
- Wheelchair carrier for disabled women to carry water.
- Bathe stool and basin stand.

Apart from easing access to proper hygiene and sanitation for PWDs, the above facilities have the following advantages for both PWDs and the community:

- PWD are able to carry out work such as sweeping, bathing, washing, and visiting latrines independently, with no, or minimum, support from able-bodied persons.
- A lot of time is saved by PWDs when carrying out their work (e.g., water collection, compound sweeping and dish washing), and they are therefore able to carry out more development activities.

- Instead of assisting PWDs with chores, such as bathing and accompanying them to latrines, able-bodied people use that time to do other developmental activities.
- The idea of independent living by PWDs is encouraged.

*(Adapted with the author's permission from an article that originally appeared UWASNET News, May 2002)*

### **Guidance questions**

The author describes an initiative developed by disabled people, for disabled people, based on local circumstances and the identified needs of individuals.

- Are there other examples of projects or initiatives, however small, that demonstrate practical solutions to access?
- When giving practical examples that you know of, it would be useful to describe, if you can:
  - Who is/was involved? What are/were their different roles?
  - Is it only a 'hardware' and technology design project, or are social issues also addressed?
  - What has been the process of implementation?
  - What problems have been encountered and how were they solved?
  - What problems remain to be solved?

## **Contributions**

### ***Paralysed hands***

*The description of possible solutions, provided in Musenyente Elijah's discussion paper, elicited the following response from Inge Komardjaja:*

I think paralysed hands is an issue that has not been raised with burning interest. Regarding disabled limbs, emphasis is on limited mobility. How people in wheelchairs, with crutches or walking sticks, and those with walking difficulties but without assistive devices are able to move around safely, conveniently, and independently provides a challenge to professionals to create a built environment that is barrier-free. How about paralysed hands? Thus far, I haven't read anything about paralysed hands. It is almost impossible to cope with day-to-day hygiene when people have paralysed hands or are without hands. I'm pleased that Mr Muhammad Mushfiqul Wara from Bangladesh mentioned the problem. In my paper I've also described the difficulty of splash-bathing with disabled hands. Mr Musenyente Elijah from Uganda enlightened me when he mentioned the toothbrush stand for people without arms. This is really a great invention, but I can't imagine how it looks like. Coincidentally, at the beginning

of this e-conference there was an image in the Indonesian newspaper about a boy without limbs whose father was brushing his teeth. They are from the low-income community. My instant thought was 'Is there a device for brushing teeth for people without arms?' We should take note of the problems of people with paralysed hands.

In response Musenyente Elijah sent photographs of the equipment mentioned.



*Blocks for keeping hands clean and toothbrush stand. (HITS, Uganda).*

### ***Design guidance and standards***

*Muhammad Mushfiqul Wara provided a detailed summary of a key design guidance manual produced in Bangladesh (DWS2 [05] – 24/9):*

#### **Design of accessible water and sanitation facilities — Bangladesh**

It has been stated that there is unavailability of information on designing accessible facilities upon which structures can be built up to assist disabled people's access to and use of water and sanitation facilities. However, this is not true in the case of Bangladesh.

In May 1997, CRP published the first edition of *An accessibility manual for people with disabilities*, by A K M Momin. Mr. Momin is the Director of CRP and currently doing his PhD in Leeds on 'An investigation of levels of

integration of people with spinal cord lesion in Bangladesh'. In his research he has used indicators which are relevant to the cultural context of Bangladesh to assess the levels of integration, e.g., personal integration and family integration, among other levels of integration required for people with spinal cord lesion to be integrated in full.

All of the following information has been extracted from this manual, which has been identified as useful for this e-conference.

For people with physiological changes, e.g., diminished eyesight or diminished hearing, consideration should be made for quality level of lighting, use of colour and contrast, light contrast and dark shadows, volume intensity and noise level, and tactual [sic] cues which can be easily read.

For people with psychological changes, (e.g., depression, insecurity, helplessness and despair, loneliness, inward looking/mental isolation, emotional disturbances, dysfunction and disintegration problems, and reduced sensory perception), consideration should be made through a design which encourages physical mobility — plan a landscaped environment with natural focal points, plan for easy recognition of spaces, particularly the use of central circulation patterns which are familiar.

For people with physical changes, (for example, arthritic hands, causing finger and hand impairment, reduction of strength and dexterity in all manual activities, reduced reaches, and arthritic feet, knees and hips with serious handicap to walking, reduced balance of body, etc), considerations should be made for light switches with enlarged rocker switches, big switch plates and clear labeling; tap heads should be substituted by screw-down taps with lever-action taps, toggle-action taps or dome headed taps; door openers should be substituted or have added door knobs with push-pull plates; larger door handles; there should be pull rails or grab handles, for vertical access, especially for the ambulant disabled, and ramps and hand rails. Again floor finishes lead to safety issues, as any falls or slips due to slippery floors and hazards may lead to serious injury for crutch and stick users. To protect from slips or falls, the floors should have slip-resistant, resilient floor finishes: carpets or cork are satisfactory for the ambulant disabled, since non-resilient surfaces facilitate wheelchair propulsion; wood/parquet is preferred for blind people.

Bathroom and toilet design should guarantee privacy and safety for users, therefore the approach to bathroom, wash basin, WC and shower (for low income communities, the bath area) must be unobstructed. For wheelchair users, space must be available for either lateral or frontal oblique transfer and there should be space for helper(s).

Bathing in a long bath or bath tub (which is not acceptable in Asia) could be more dangerous for people with certain disabilities, and therefore hand rails

will be required to assist in supporting the users.

A practical water port requires wet bench/seat showers, which is preferable to baths, can have adjustable height for a portable shower spray on flexible hose, detachable hand control, requires wet shower seat, and requires vertical and horizontal rails [sic].

In considering a wash basin, the underside of the basin should be high enough to clear thighs. The shape of the basin should be wider from front to back for users to accommodate hand, face and hair washing. No shelves should be out of reach of the user, a mirror should be above the basin, and the basin should contain an attached sink plug.

Water closets could be of two types: seated type and squat type. The seated type could be a pedestal seat with enlarged bench instead of a seat. Several support rails could be used; horizontal rails, vertical rails, slightly inclined rails, hinged or pivoted support rails, removable or portable support aid, side support aid, and hanger to lift.

A standard range of dwelling types could be developed, to suit the majority of disabled people and household sizes, which can be fine-tuned in case prospective disabled occupants have not been identified before designs are commenced. Keeping this in mind, the author recommended some necessary standards, which have been adopted in many countries of the world.

### *Kitchens*

Each kitchen should be made to suit the individual. Planning considerations are a minimum amount of space (movement) and easy transfer between surfaces. A kitchen layout in an 'L' or 'U' shape is preferable to a line layout, in order to minimise wheelchair movement. Grouping of activity areas, (cooking, washing, etc), may also help. A space between the fronts of units of 1.2 m allows sufficient transfer and turning area, giving a total kitchen width of 2.2m to 2.4m minimum.

Particular points to note for a kitchen:

- General adaptability height, weight, flexibility in tight spaces.
- Ease of operation catches, pulls, drawer sides.
- Smooth/round vulnerable angles.
- Good toe recess where floor mounted.
- Range of fittings, pullout boards, shelves on doors.
- Scope for incorporating services and controls.
- Work surface recommend width = 0.6m
- Work surface height = 0.6m - 0.8m
- Pullout surface height = 0.57m - 0.71m

Work surface heights:



- Fixed or adjustable seat, alternative is a mobile shower chair.
- Shower area: 1.2m x 1.2m.
- Sloping floor 1: 40 - 1: 50 with trapped outlet.
- Non-slip waterproof covering and shower curtain.
- Adequate water pressure.

### *Bath*

Various bath sizes are available:

- Typical length = 1.5m - 1.7m.
- Width = 0.65m - 0.750m.
- Bathtub depth preferred = 0.45m from floor to allow easy transfer from a wheelchair and minimum 0.3m.

The choice of size will depend on individual preferences. The bath should be flat-bottomed and drop-sided, with handgrips mounted on the wall (handgrips on the access side of the bath can be an obstruction). The slope of the bath should not be too shallow and rim height of 0.41m is suggested.

### *Hand basin*

Owing to the variability of wheelchair users, there is no fixed height for wash basins that will be generally convenient. In housing for disabled people, it is preferred that the fitting of the basin is delayed until the optimum height for the disabled user is established. If this is not possible, the basin should be fixed, and then altered subsequently if necessary.

For chair users a convenient height for basin rim is approximately 0.67m - 0.82m. Where the basin has to be fixed in advance, use a rim height of 0.75m.

For ambulant disabled people, a basin may be fixed at varying levels, such as 700mm, 800mm and 900mm. Basins at lower levels are more convenient for children and wheelchair users. Mirrors should have adjustable heights.

### *WC*

A standard WC compartment size is 2.0m x 1.5m (recommended for public buildings) which allow transfer either laterally across one side of the wheelchair, frontally or obliquely. The smallest WC compartment size is 1.7m x 1.4m or 1.6m x 1.5m. This also allows sufficient space for a man in a wheelchair to manoeuvre and position himself to use a urinal.

The cistern and WC pan should be kept at a suitable distance from each other to facilitate easy use by disabled people. The cistern should be operated by a lever handle and the recommended toilet rim height is 450mm, giving a seat height of 475mm. The central heating radiator should not be sited next to the WC. If there is more than one WC in a dwelling, the controls should be identical to avoid confusion to visually handicapped people.

Rails should be provided at the side of the WC as standard. Failing this, space should be allowed at the side of the WC so that a grab rail can be fixed later if necessary.

There is a misunderstanding among people that a barrier free environment would cost a lot. This is not true, in fact it costs considerably less than adapting later. It is important to know that designing to barrier-free standards need not necessitate increased overall areas, but rather thoughtful planning and thoughtful use of the available space. This does not increase the cost of the building. The only internal requirement which may have cost implications is the need for 0.9m-wide door frames. Some houses and flats are designed in any case with 0.9m overall doors, but the difference in cost between 0.8m and 0.9m-wide doors is not great. The provision of WCs on the ground floor of a two-storey house is of benefit to everyone. The barrier-free need is that it is accessible to everyone. Again this is something that can be achieved by thoughtful planning.

The cost of different ground floor constructions, external steps, etc, depends on site conditions. On a flat site, where a solid floor construction was to be used in any case, barrier free standards could be achieved with no extra cost. On sloping sites extra cost will be involved in creating a barrier free environment, but as with all things, the cost involved has to be weighed against the ensuing benefits.

In general terms, it is not possible to state a difference in cost between housing designed to barrier free standards and 'ordinary' housing, as 'ordinary' housing varies widely and may by chance be barrier free. Much can be done to make housing more accessible to people with disabilities at very little extra expense.

In conclusion, the author states that:

'The idea of fitting buildings or equipment so that they actually suit people is relatively new, and so is the concept of ergonomics by which it is known. Apart from those in wheelchairs, people with disabilities do not pose new problems to the architect but only acute cases of existing ones. The able-bodied person is liable to slip on a polished floor, topple over in the bath, trip over a sill or walk into a glass door. Ways of countering dangers do not alter if consideration is given to people with disabilities, they simply become more significant. What might be a useful bonus becomes a prerequisite; e.g., non-slip floors, low level shelves, manageable window openers, intelligently ordered kitchens and rails for support by the bath. Given that the needs of disabled people are, by comparison with those of able-bodied people, simply a matter of degree, the only reasonable excuse for not taking account of them is finance. It is cheaper to put in a staircase than a lift. Cost controls are of course unavoidable, but they

ought not to be so constraining that they encourage a lack of regard for the elderly and disabled’.

In this publication, some standards are recommended which are accepted for the disabled throughout the world, and compared with the BNBC. From the comparisons shown here it can be seen that only slight changes are required in some cases, and in other cases changes such as fittings, control heights, contrasting colours on stairs, doors etc, should be included in the BNBC. Most areas of the environment are mentioned here; for the sake of development, progress and equality, they should all be considered for inclusion in the National Building Code.

NB. In the last National Level Accessibility Workshop held on 29 June 2002 at CRP, in which 112 participants joined, (including engineers from Government and NGO institutions and programmes), this manual was highly praised and ensured that some of the relevant recommendations will be implemented by the Government.

*Hazel Jones (DWS[2] - 26/9) raised some questions in relation to this contribution.*

Who are these guidelines aimed at, and who actually uses them? Are they aimed at disabled people to adapt their own homes, or at CRP professionals — OT or community workers — or at architects/ engineers/builders/plumbers? Do you have examples yet of people who have used the guidelines and how?

The reason I ask, is because in the course of this research on accessibility to water and sanitation I have been reading about the issues from a variety of points of view. As someone with an education/community development background, I find that documents written for other professions (e.g., engineers, OTs, geographers, etc) are not always user-friendly for me, they use difficult language that I find can be off-putting to me. Maybe I am just lazy (!), but actually I think it is a common problem that we need to be aware of, if we want written materials/guidelines actually to be used.

Another issue that I've found in this research is that there are some areas where there is a real lack of information about access for disabled people: collection from natural water sources, wells, tap-stands, transporting water, storage and accessing stored water in the home, and household waste disposal. I wonder are any of these issues addressed in this manual?

NB: Incidentally, for those with Internet access, the following documents can be downloaded; they have similar type of guidelines, with diagrams and detailed specifications. They are very much based on Western urban built

environments, and for rural or slum environments I imagine would need a huge amount of imagination to adapt them.

UNESCAP (1995a) *Promotion of Non-handicapping Physical Environments for Disabled Persons: Guidelines*. UN New York. [ST/ESCAP/1492]

<http://www.unescap.org/decade/publications/z15009gl/z1500901.htm>

UNESCAP (1997) *Production and Distribution of Assistive Devices for People with Disabilities*. United Nations: New York. [ST/ESCAP/1774]

<http://www.unescap.org/decade/assdev-index.htm>

*During Theme 3, Muhammad Mushfiqul Wara provided the following clarification (DWS3[09] – 7/10):*

*An accessibility manual for disabled people* by Mr. A K M Momin was prepared targeting professionals, OTs, engineers and builders, and consulting firms and organisations that work with disabled people, to provide them with technical information about accessible built environment. When it was developed it did not directly target disabled people, but disabled people can easily use the information presented in the manual.

This manual has been disseminated to government and professional organisations which are directly involved with accessibility issues. So far 1000 copies have been sold to different organisations like Local Government Engineering Department (LGED) which purchased about 300 copies for all of their Upazilla (sub-district) level engineers and organisations working with disabled people including some professional organisations. CRP publicised this manual to government agencies, and to ensure implementation at the local government levels, it organised several workshops where professionals showed their interest in using the recommendations provided in this manual. The LGED is in the process of implementing the recommendations through their engineering work plan. The Ministry of Works showed interest to pursue this issue further and CRP is following this up with the Secretary of Works Ministry and others.

This manual mainly focuses on built environment, not particularly water and sanitation areas; however, in many sub-sections of this manual some of the water and sanitation issues are covered.

In Bangladesh, the problems of inaccessibility are very basic and one of the most severe problems that affects participation of disabled people in many ways. When disabled people have access within their home environment, many other issues could be brought to the mainstream of the society.

## ***Assessing access***

*Muhammad Mushfiqul Wara submitted the following paper on 'Identification of the actual levels of access and use of domestic water and sanitation facilities of disabled people in low income communities using FIM based on ICIDH-2 with practical research variables to compensate with the current lack of data' (DWS[6] – 24/9):*

The issue of water and sanitation in relation to disabled people is very new in the context of Bangladesh, though this affects the following levels of integration: personal integration, family integration, and social integration/community integration of disabled people.

The levels of integration of disabled people in the communities are institutionally measured, usually by the Functional Impairment Measurement (FIM), which includes activities of daily living as a major component. Institutional-based rehabilitation is planned based on the score of FIM in many cases. Components of ADLs used as measures of FIM score differs from culture to culture. Institutional rehabilitation professionals should consider involving the issues of access and use of water and sanitation as a measure of FIM. Sharing of experiences with disabled people may help them to develop a FIM for a specific culture, which can be tested. An ongoing study on levels of community integration of people with spinal cord lesion in Bangladesh used some integration measures that have included some activities related to use of water and sanitation. The results and findings of the study may be a reference point for further studying of the issues of integration of physically impaired people in the areas of water and sanitation. The study has focused on gender differences and the approach being 'emancipatory', it discloses the actual experiences of disabled people in the communities in which they have lived.

The ICIDH-2 [see glossary] — some of the activities listed within the 'Self-care activities' could be used as a standard in the process. The current studies looking at levels of adaptation/integration in the lives of disabled people, will be used for finding out appropriate variables to develop a questionnaire. This can be regularly administered, in order to collect data from disabled people seeking OT services through which rehabilitation could be provided, before integrating them within the community. CBR workers can take appropriate steps to get to the appropriate service providers, with the involvement of community people.

In many cases, the OTs state that they assess the functional abilities of disabled people upon which they base appropriate interventions. From my experience, I have seen that this is not the case in that self-care activities, which may be relevant for using water and sanitation facilities, are not focused on. Therefore, the actual state of disabled people regarding access to and use of water and sanitation is not available in documents which may be very

necessary when a programme inception is considered.

### ***Local solutions***

*Musenyente Elijah responded to Md. Shamsur Rahman's contribution (DWS2[02] – 19/9) on hygiene, access and use of water and sanitation facilities at home by physically impaired women, (DWS2[09] – 26/9):*

Like in Bangladesh, Uganda has similar problems, worsened by unhealthy cultural practices. There is a need for community sensitisation on proper hygiene and sanitation. What our organisation (HITS) is trying to do is to demonstrate to the community that construction of a pit latrine or a bath shelter is not as expensive as the community thinks.

These can be constructed using the locally available materials, at very cheap labour costs. As for the disabled, HITS designed handles for hands, made out of wood, and 'knee covers', made out of used tyres, to protect a crawling disabled person from contamination in unhygienic places.

In Uganda's low income communities, disabled people with back-borne damage have no access to proper hygiene and sanitation. Uncontrolled urine, and how to activate the digestive system to be able to visit the toilet, are major problems. I wonder whether there are some simple facilities to cater for these disabled people's proper hygiene and sanitation?

*Md. Mahbubul Ashraf (DWS1[07] – 16/9) introduced Bangladesh Protibandhi Kallyan Somity (BPKS):*

It is the only cross-disability self-help organisation of the persons with disabilities in Bangladesh. It has been working for the last 17 years and solely comprises disabled persons who have been working for all of the community.

BPKS has taken some initiatives to ensure accessible tube well and sanitary latrine facilities for the rural disabled persons, children and pregnant women. One Family International of USA has been in close co-operation with us in this regard. As we have some practical experiences in this area we are interested to share our experiences with others and gain new ideas. Our innovative and cost effective approaches are going to be implemented in other developing countries like Tanzania.

## Appendix 4.

### **Theme 3 — tools to support improved access to water and sanitation facilities (strategies for the future)**

#### **Introduction**

There were 17 contributions under this theme, 11 of which were submitted after the official closing date, indicating that this is an issue that will continue to be debated.

#### ***Discussion paper***

*Hazel Jones, Research Associate, WEDC.*

The research project 'Access and use of domestic water and sanitation facilities for disabled people in low-income communities' has started by carrying out a review of available information — published and unpublished — relevant to the topic. The purpose of the review was to check that we are not repeating what someone else is already doing, to show gaps in information that need to be filled, and to identify existing knowledge and practice that this research could build on. The review report will be available shortly. Meanwhile, here are some of the main issues and questions that have emerged:

There is a lack of relevant and available information describing examples of good practice, especially in the following areas: improving access to natural open water sources; access and usability of wells, hand-pumps, tap stands, rainwater collection systems; transportation and storage of water; access to stored water; and accessibility of household refuse disposal systems.

It is possible that these are areas in which nothing has been done, but it is more likely that knowledge and information does exist, but is not written down. Some of the most useful and relevant information has been sent in directly by practitioners and disabled people. What has been disappointing has been the lack of response to calls for information from water and sanitation professionals. A literature review is only one way of collecting information, and is limited in many ways. Alternative ways of collecting and documenting information need to be explored.

#### **Broadening the target audience**

The project's original focus was on organisations working with disabled people and their families, to support them to provide individual solutions. The literature review shows that focusing on the individual person's limitations is not

enough, but that a 'comprehensive' approach is needed. This needs to include accessible and inclusive water and sanitation facilities, in other words, disability needs to be 'mainstreamed' — a process which is already being used for gender issues. Water and sanitation facilities are the responsibility of infrastructure service providers — engineers, architects, planners, etc. There is, therefore, an urgent need to provide information and tools for these technical professionals.

### **Lack of resources and information for practitioners**

There is, firstly, a lack of easily obtainable information to support people working in this area, and secondly, a lack of information in appropriate user-friendly formats. It is important to identify the different kinds of information and formats that different sector practitioners need, e.g., engineers, therapists, disabled people's organisations. Equally important is to identify effective dissemination strategies, so that people who need the information can get it easily. Electronic formats have many advantages, but they do not suit everyone, so alternative dissemination paths are still needed.

### **Holistic view of barriers**

Barriers to disabled people's access and participation need to be viewed holistically. To address certain aspects, e.g., individual physical limitations and barriers in the physical environment, whilst ignoring social and institutional barriers, is likely to provide at best only short-term benefits and at worst prove ineffective. Different sectors need to co-operate in addressing these broader social and institutional issues.

### **Project scope: displacement/institutions/geography**

The focus of this project is primarily on disabled people in a family context, but the need for access to water and sanitation is equally pressing in other contexts, such as health and educational institutions, and displacement through conflict or disaster. Some support materials are likely to be universally applicable, but it may not be possible to address all the particular and unique issues that arise from each of these specific contexts.

In spite of the wide range of geographic contexts, and cultural perceptions of disability, there appear to be some broad principles and processes involved in identifying and meeting the needs of disabled people, that can be applied globally. Some of the principles of appropriate technology and equipment are universal, but local cultural perceptions and norms mean that designs still need to be adapted to suit local circumstances.

It is a challenge to produce materials that strike a balance between the local and the universal: on the one hand that have relevance to disabled people

globally, and on the other that encourage the development of local solutions and adaptations.

### **Key role of disabled people**

All the literature confirms that the effectiveness and sustainability of projects is improved when disabled people participate actively in all aspects of the project cycle. Where the goal of research is to improve the well-being of disabled people, the process of the research should therefore also contribute to this. The project needs to consider how to consult and involve representatives of disabled people at different stages in the research: planning, field work, data analysis, and dissemination of information.

### ***Guidance questions***

- What strategies and actions are needed in order to move things forward?
- Who needs to be involved in carrying these out?
- How can this research project usefully contribute to supporting such strategies and actions?

## **Contributions**

### ***Information***

*Inge Komardjaja followed the discussion paper with the following comments (DWS3[02] - 30/9):*

I fully concur that dissemination of information is very important to make disabled people aware of available access and facilities. Following are some thoughts:

People in low income communities are often behind because of lack of information. We need, however, to be culturally-sensitive in how information can be effectively disseminated. It is not always the case that written information is effective in low income communities. In Indonesia, based on my experience, talking to people, accompanied by demonstration, seems to be better understood than letting them read pamphlets or guidelines. The culture here is more of talking and listening, rather than writing and reading. Another effective manner is through a play or show. For example, to mainstream disabled people in low-income communities, it could be done through the art of puppet shows.

In low income communities there are skilled labourers, who can build, for example, barrier-free bathrooms if only they are made aware of the need of

disabled people. There is no need to have an architect or construction engineer to build the special facilities for disabled people. They are more expensive than skilled labourers, aren't they? For the skilled labourers, the principle of 'learning by doing' should be applied instead of providing them with written guidelines, which often use so much jargon.

### ***Visually impaired users***

*Donatilla Kanimba provided us with an insight into some of the barriers that visually impaired and blind people encounter when accessing or using water and sanitation facilities (DWS3[06] – 04/10 – see Appendix 2)*

*In the remainder of her contribution she discusses reasons for poor participation of sensorially impaired people in this e-conference and offers some suggestions for improving access to water and sanitation.*

My worry is the fact that there has been very little contribution from people with sensory disabilities. I believe that part of the reason is that many of them, especially those who are blind, are not aware of this conference. The fact is, the number of organisations of the blind around Africa and the developing world, which can have access to email are quite few, considering the fact that some modifications have to be made to make it user friendly to a blind person.

On the question of water and sanitation for blind people, as it was mentioned before, it is very difficult to find solutions which will suit every disability and all cultures at the same time. However, it is possible to group certain cultures together. For instance, solutions to problems of blind people south of the Sahara in Africa will suit most of the rural population in this region, because lifestyle in this region is very similar: such as fetching water from wells, rivers and lakes or public taps, using pit latrines, lack of running water in the home and so on. Solutions therefore must be considered with specific target groups in mind, and it will be more relevant if the target group is consulted in the development of any product or adaptation.

*With reference to the problems that she outlines in Appendix 2 (that visually impaired people have difficulty knowing which tap is hot, how to operate a strange shower or how to avoid stepping in a pit latrine hole), Donatilla says:*

All these are problems which can easily be solved:

- A landmark, like a different feel to the floor when approaching the hole, or a slightly raised floor for the hole (not a step).
- Internationally accepted feel for hot water taps.
- Information in hotels and such places in Braille or audio,(cassette). If televisions can be provided then surely tape-recording is not more expensive).

All these would make life a lot easier for blind people.

*Muhammad Mushfiqul Wara responded:*

The same problem of communication among the NGOs in Bangladesh was experienced — 170 NGOs are linked with the network from where we got the e-conference news, unfortunately only 37 of them has email, so the rest could not know about it. We had the same problem when CRP wanted to contact NGOs which were working in the area of water and sanitation, the limited email numbers limited our opportunity to find out interested organisations to contact for further reference on the research project.

There are certainly some similarities in the problems of the disabled people about water and sanitation but it differs according to the impairment levels and severity and also with the environment in which they live. The OT will be able to identify the world view of disabled people and explore the activities people might like to do and thus modify their environment — the same goes for water and sanitation. So the involvement of disabled people and the professionals will be required to do a comprehensive assessment of the problems. Only then will we be able to provide 'service' in the area of water and sanitation, matching the needs of disabled people in the low income communities.

Recently in Bangladesh, water and sanitation services are provided by both NGOs and GOs, therefore future services should not detach them, rather the services needs to be co-ordinated with the community people, with the involvement of disabled people. The self-help groups of disabled people have termed service providers' attitudes as 'specialised attitude' and asked them to learn how the real services could be provided.

### ***Ugandan perspective***

*Musenyente Elijah (DWS3[03] - 2/10) outlines clearly some strategies for improving access and use of water and sanitation in the future.*

1. Collective effort by all stakeholders in information collection and dissemination.

Information on individual or particular needs of disabled people in accessing water, hygiene and sanitation is an important basis for the invention of new facilities or for identifying the existing facilities to solve the problem. The problem lies in obtaining information from individuals around the world.

I suggest an increased global sensitisation to create awareness of the problem through government, civic leaders, religious leaders, community activists, cultural leaders, communication media, workshops/conferences, etc. Plus there should be active participation by the disabled themselves, their families, the

community in which they live, researchers, service providers e.g., engineers, architects.

2. Setting up voluntary information centres/representatives at local or universal levels, so that information can be obtained on access to water, hygiene and sanitation for the disabled — this will help to consolidate all the information and trickle down this information to all those who need it.
3. Direct involvement of disabled in planning, field work, information dissemination, data analysis, etc — this will act as an incentive and provide a feeling of ownership in dealing with the problem.
4. Breaking of cultural/social ties which do not conform to proper standards of access to water, hygiene and sanitation for the disabled — this can be done through community sensitisation, but beginning with the sensitisation of cultural and community leaders.
5. Balancing between local and universal facilities, putting into consideration the affordability — the facilities for disabled people should be strong enough to avoid accidents and also cheap/affordable by the disabled. Further, the facilities should conform to one's disability, with considerations such as ramped access, wide entrances, height of borehole, etc.
6. Addressing access to water and sanitation for disabled people at all levels — i.e., family, public places, displacement through conflict or disaster, etc.
7. Adapting existing facilities through modifications to suit one's disability.
8. Pushing for Government involvement.

### ***Bangladesh perspective***

*Md. Abu Zahid, whose personal account of having a paralysed hand can be found in Appendix 2, suggested:*

People like me would be doing wonderfully if they had a 'hose' pipe linked to the tap of supply water to clean them up after latrine use, and use of sanitary paper. If one hand works they would not have any problem in using a pump to collect water, or using a tube well.

## **Paper on strategies and tools to improve accessibility for disabled people in water and sanitation**

Contributors:

- Md. Shamsur Rahman
- Md. Sahadat Sarwar
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- Muhammad Mushfiqul Wara

An appropriate strategy must consider the problems with the service providers and the relationship between service providers and service users. The next few paragraphs will look at the interaction between these two stakeholders, which if remedied, will make the specific strategies and tools recommended useful.

When developing any strategies for re-integrating disabled people in the community, the availability of basic facilities should be considered first. We like to talk about designs, tools and equipment — implementation of which will be very costly — so we should foremost consider the sources of resources to help use these technologies. Professionals are often bogged down with specialisation, and testing the uniqueness of their inventions to prove their authority in an area. The specialised service is designed for disabled people, many of whom suffer from hidden barriers. The projects should look at specific issues, and at the same time must consider the basic needs of disabled people. For example, the projects of water and sanitation services should specifically look at the issues of living and treatment before being assessed for water and sanitation services. In many cases, water and sanitation services will depend on some primary rehabilitation interventions, to help disabled people make effective use of the project.

The primary rehabilitation of disabled people, before any effort is given to water and sanitation, should be considered seriously. There is no doubt that disabled people require this rehabilitation from the physiotherapists and OTs. There is a great shortage of these professionals in our community; numbers cannot be increased in one night. Alternative methods of educating disabled people to help themselves in their home environment may also be helpful. (This is what some service providers are currently offering, however, they are not involved in the area of water and sanitation.) Two alternatives are; carers could be trained in the area of assisting family members; or the traditional healers in the community could be trained in basic skills of helping disabled people with rehabilitation services.

There has been a trend of involving communities in the service provision (which disabled people are nominally involved in), that has resulted in little real service to disabled people. However, increasingly the involvement of self-help groups of disabled people is considered in the areas of service provision. The objective of involvement of self-help groups is to bridge the gap between

service providers and real service receivers. This will also encourage disabled people to believe that an environment has been created in which they can speak about their problems and that someone is listening. If this encourages them positively, then the secondary involvement of the service providers will appear. The service providers will then get to know the actual problems and requirements of disabled people, on which strategies and action plans could be developed, following the services. Moreover, none of the strategic planning will be effective if resources are not properly mobilised. This will only be usefully collated through involvement of all related stakeholders — from disabled people, their family members, community people, service providers at the community level and the government.

CBR has no alternative at this stage. However it is very important to modify the approaches of the CBR programmes. The experience of disabled people of the CBR programme is that these programmes have often failed to mobilise the resources from the community. The reason for this failure is that the objectives of the service providers and the potential service users do not match. Service providers are often interested in developing themselves at the super-structural levels (meaning developing links with government agencies and officials which in future help them to take up programmes in more areas), which disadvantages disabled people more, since the hopes of disabled people are nipped in the bud. Specifically, this is the attitude of service providers who have in mind the 'top-down' process of operation. This should be modified to a 'bottom-up' approach, which directly involves disabled people in the initiatives.

Another drawback of the programmes is that they are often quantitatively evaluated — 'numbers of people given the service' — which is rarely useful for improving the quality of life of disabled people. Instead a 'qualitative method' of evaluation should be taken up, which will elaborate on 'how the given services have brought in changes' in the lives of disabled people.

The available information does not reflect the understanding of disabled people. Some of the research studies completed until now do not reflect the situations of disabled people. Some studies are ongoing, looking at the re-integration issues of disabled people in the community, which also do not consider the problems from the point of view of disabled people. For example, the review undertaken by the WEDC has not considered the involvement of disabled people's world of concern, and is mostly professional-oriented. Disabled people need to be involved in the process of research all along — information should be collected from disabled people and be presented to the disabled people and the community services providers. The information also needs to be collected by disabled people so that the real issues for disabled people are not overlooked.

NGOs often say that they are non-profitable. However, due to the pressure of the donor for 'self-sustainability' criteria, NGOs become commercial

enterprises. In many cases, although they say that they develop assistive devices using locally available materials and skills, they seem most interested in developing such models which they can sell at higher prices. This sort of equipment becomes so costly for disabled people that few can actually use them. The opinion of the service providers seems to be that they have to become self-sustaining at a certain time, and are obliged to develop materials that can bring them some sort of 'sustainability' in the programme when funding gets reduced. Also the availability of appropriate knowledge and skills required to market 'cheap' equipment with locally available materials need testing — but funding is very limited.

There is a huge gap of information between service users and service providers. Often the disabled people living in the community complain that they do not know what services are provided for them. However, service providers say that they have circulated the information to the disabled people and in most cases to the community people too. The reason behind this misunderstanding is that service providers do not consider the priorities set by disabled people, but are only interested in collecting information which is valuable for them. This is what the self-help group leaders term 'specialised attitudes' of the professionals. This attitude is reflected by provision of prescription for disabled people. The World Health Organisation (WHO) estimate, of about ten per cent of people having some kind of disabilities in the developing countries, is a joke in Bangladesh, because people do not understand from whom the data was collected — they do not know of any time in their community when data was collected for this report! What secondary sources were used, did those strategies produce fact? They identified people who were disabled; rather than asking people if they thought they had any kind of disability!

Such a lack of information is huge. Service providers still need to re-consider the most effective means of disseminating information. Service providers have used numerous methods of dissemination, many of which failed to reach the people for whom it was designed. That is why, when the programmes are evaluated, often it is found that the objectives of dissemination of information could not be met. Most often the method of dissemination is not suitable for the groups of disabled people (language, pitch of information, cost, form in which information is presented, cost to acquire the information package, usability, feedback systems, etc) which is related to acceptance of the information by target groups. The method by which information is usually disseminated to the target people is through associations of NGOs (restricted to advantageous NGOs or government departments), which then distribute the information to lower level NGOs sharing the same mission/political orientation. A lot of NGOs are left out because they do not have, in most cases, office amenities (e.g., telephone number, email address) that can be listed in a directory of associations.

The image of service receivers is still not high in the 'cognitive world' of the services providers. The service receivers are still undermined and thought of as dependent on the service providers. This kind of attitude needs immediate alteration to learn what a real 'service' means. An editorial titled 'Doctor - Shopping' writes

‘...what is worse not many of our [practitioners] are sensitive... Practitioners here are not exactly famous for attractive public relationing exercises... Perhaps our good [practitioners] would try mending their manners as a first step in winning [service receivers]...’

(*The Bangladesh Observer*, Dhaka, Tuesday, 24 September 2002).

The following paragraphs will look at some specific issues relating to the areas of water and sanitation. This will provide the current situation and the possible solutions to overcome them.

### **Rainwater collection system**

Due to arsenic contamination many tube wells have been red-marked by the Public Health Engineering Department and NGOs. It is worrying that many people are still using water from red-marked tube wells because of a lack of awareness of the 'level of harm' when used. People do not see any immediate symptoms so they are prompted to use this contaminated water. Again many people who are having tube wells set up at their households, are not having any laboratory tests for arsenic done on the water, since the test costs them \$5 to \$10, which is unbearable for low-income people. Alternative uses of water are blocked for them as well. The other natural water sources are contaminated too. Ponds, tanks and river water is contaminated by sanitary refuse and household waste, small and big industrial waste, etc. There is little movement towards water waste recycling systems and little technology available in both urban and rural communities. Moreover, there is an accessibility problem to reach natural sources of water due to rough, swampy, slippery paths, and steep edges, and non-availability of appropriate mobility aids/assistive devices to help these people collect water from these sources. Professionals say that these sources are 'safety' problems for disabled people if they do not have adequate assistive devices to protect them from falling.

Rainwater, however, could be a good source of water collection for low-income people, and for rural Bangladesh it could be an advantage since many of the households have corrugated iron sheet roofs. The edges of these corrugated roofs could be linked with a drain that will help collate all rainwater into a cement tank during rain. Compared to the other sources of water, collection of rainwater is easy and cheap. The most limitation will be for those countries where rainwater is very limited, for Bangladesh this is an advantage.

In the urban communities, water collection is a problem. The Government-installed taps are ill-working. In this case, rainwater could be collected by co-ordinated efforts of GOs and NGOs which are involved in the areas of water supply and sanitation services. Buildings could be sources of rainwater collection through pipes. We have heard in Bangladesh so many times that the Government has talked about this issue, but unfortunately we have not seen any significant initiatives from them. Now, when disabled people collect rainwater following this method, they face the challenge of learning how to purify rainwater. Precautionary measures to protect from contamination need to be taken as soon as people think about using this method of collecting water for use.

### **Household refuse system**

The household refuse disposal system is an environmental problem. This problem is at its peak during the rainy season and during floods. Due to environmental change in Bangladesh, and globally, Bangladesh is suffering frequently from disasters, of which flood is common. Due to global warming and the sharing of international river water, the 'height of water at river' has become a problem. It is for the international community to solve these issues, which are absolutely not in the control of the communities. At the local level we should take up some necessary measures to protect our people from being prone to adversities during flood. NGOs working, maybe in the field of disaster management, can take up programmes or modify their programmes for vulnerable disabled people and their communities to focus on this problem. Specifically, household refuse disposal systems need to be considered all year round. Not all people in the community carefully dispose of household waste. Because household responsibility is on women, they are mostly the ones disposing of household refuse beside or at the back of the houses or in the ditch. For them awareness of hygienic living will be useful. Only a few households, which grow kitchen gardens at their yards, dump household waste and kitchen waste in these ditches, which they cover with earth to develop manure. There needs to be awareness of community people about hygienic living practices. People could make themselves aware about living hygienically as it was stated in an editorial in 1956:

'People can not be forced to practise hygiene but they can be instructed to think hygienically, which is tantamount to saying that they will learn to live hygienically. This may be some of the knowledge imparted to the people... when then generally accepted and practised, will do much to eliminate unnecessary diseases to so many of us have come to accept as being inevitable'  
(*The Observer*, Dhaka, 24 September 1956).

### **Involvement of disabled people in the water and sanitation research project**

There has been a very proactive thinking by the e-conference facilitator to explore the information from the published and unpublished. The conference participants have so far tried to give as much published and unpublished information and thoughts from their levels of orientation and authority. Still there is need to explore the 'unearthed' experiences of service providers; both those with direct experiences in the field of water and sanitation services and those who do not have such experience, but are either experienced in working with disabled people or with the community as a whole. An opportunity must be created involving the service providers and the service users (or potential users), so the issues raised by non-professionals could be checked with the professionals, if they are interested in launching programmes to address the problems and move forward with 'mutual' strategies.

At the grass roots level, involvement of disabled people will also be essential, as we said about the representation of disabled people at different levels of planning, fieldwork, data analysis and dissemination of information. It is also very important to arrange open discussion/ workshops at the community level to share the whole process of this research project. The associations of disabled people (self-help groups of disabled people) could be involved in organising and arranging these. The workshop recommendations could be extended to the community level with a 'baseline' survey of households of disabled people, to identify the actual problems relating to water and sanitation and the way they feel the problems will be solved. Professionals' involvement will be required in this process of assessment as well. The self-help groups of disabled people will still be required in the process of disseminating the information of the research findings. They will, if they are assisted to do so, be able to play the role of producing community awareness programmes. The self-help groups of disabled people should also be treated as 'panels' in the process of evaluating the effectiveness of the programmes. Since the self-help groups of disabled people will be the members of the panel, they will have been involved in the process of fieldwork and data analysis.

*Lena Nielsen from Denmark added the following contribution (DWS3[12] – 7/10):*

I just want to state, that one of the most fair and effective tools to ensure access to water and sanitation is to contact disabled peoples organisations in the country concerned. Always consult directly with representative disability organisations — involve them in the decision-making process on these issues, i.e. organisations of disabled persons themselves and their families. It should be a requirement that technical professionals have regular meetings with DPOs in the country concerned.

Would it be an idea — in co-operation with us — to ask our host, The Water Engineering and Development Centre, to formulate a draft for a sort of ‘Guidance Note: aimed towards the technical professionals and staff working in the field of water and sanitation’?

The target groups for the ‘Guidance Note’ might be technical professionals, engineers, architects, planners, sponsors, staff working in development co-operation, disabled people’s organisations, District Assemblies, stakeholders, etc. It could contain key working principles and detailed practical information and ideas to ensure access to water and sanitation for all the different groups of people with disabilities.

*Several contributions followed this line of discussion.*

*Inge Komardjaja (DWS3[13] – 8/10):*

Your suggestion is very useful. Perhaps there should be two kinds of ‘guidance note’: one for the North and one for the South. For the South I suggest the guidance note should contain photos and simple drawings of various tools and minimum use of language, for example a clear photo or drawing of the tooth stand device invented by Mr Musenyente and his team. The original draft is of course in English and with permission of WEDC I’m willing to translate it into Indonesian by mentioning its source (I hope I’m not reacting too quickly). Then I’ll forward the original and translated versions to my institute and NGOs. What do you think?

*Lena Nielsen (DWS3[14] – 9/10):*

As the theme is access to water and sanitation facilities in low-income communities, I think a possible ‘Guidance note’ should cover the South only. Your suggestion of drawings and photos is of great value to the form and content of the document. I have seen this model in some books written by The Hesperian Foundation, the titles being: *Where women have no doctor*, *Disabled village children*, *HIV/AIDS in your community*, etc. If you have access to internet, information can be studied at the web site: [www.hesperian.org](http://www.hesperian.org)

*Inge Komardjaja (DWS3[15] – 10/10):*

Suddenly I recall that I have the CD-ROM *Community Development Library* which contains among others sanitation and water in the South. The information is not so related to disabled people, but perhaps the drawn facilities can be adapted to the condition of disabled people. There is a small section on disability issues though. This CD-ROM was released in August 2001 and I think you can get it for free (I got it for free). These are the details:

Human Info NGO (Humanity Information Projects), Oosterveldlaan 96, B-2610 Antwerp Belgium, Tel 32-3-448.05.54, Fax 32-3-449.75.74;

E-mail: [cdl@humaninfo.org](mailto:cdl@humaninfo.org) Web [www.humaninfo.org](http://www.humaninfo.org)

They have many kinds of CD-ROMs, such as *World Environmental Library*, *Medical and Health Library*, etc, but none about disabled people. Perhaps WEDC (and the participants of this e-conference) can produce a CD-ROM named 'Water and sanitation facilities for disabled people in the South'. Is this too ambitious?

*Karen Reiff, The Danish Council of Organizations of Disabled People (DWS3[16] – 10/10):*

First of all I strongly support the previous comments regarding the involvement of organisations of disabled people to ensure access to water and sanitation.

This e-conference has already shown us that it is people with disability themselves who know what kind of needs and request they have regarding water and sanitation.

I also support the idea of a guidance note, which would be an important tool not only for professionals, engineers, architects, planners, etc, but also for the organisations of disabled people themselves. However the guidance note should not only cover the South as suggested in previous mails, because there are countries in Europe, such as Bosnia, which could benefit from a guidance note as well. Especially because these countries are undergoing a huge reconstruction process, which includes building new schools, hospitals, health posts, municipalities, etc.

## Appendix 5. List of contributors

The following are based on the personal introductions made by participants: Full introductions can be viewed in the archives at [www.jiscmail.ac.uk/lists/dws.html](http://www.jiscmail.ac.uk/lists/dws.html)

**S. M. Mohorom Ali**, is a peer counsellor for CRP, Bangladesh, but has also worked as Finance and Service Affairs Secretary for a self-help group. He has trained disabled people at community levels and participated in rights-based campaigns for disabled people. (DSW01[03] – 12/9/02).

**Amritya Chandra Barman** is a Self-help Group Leader from Gazipur, Bangladesh who is trained in computer applications. He wants to bring in rights-based changes in the lives of disabled people. (DSW01[03] – 12/9/02)

**Musenyente Elijah** from Uganda became disabled at the age of four, as a result of polio. As a child he moved by crawling, but now as an adult he uses a wheelchair. He studied in schools for all, and then worked with an NGO for disabled people. He later founded HITS, represents the disability thematic group at the Uganda National NGO Forum and sits on the water, hygiene and sanitation technology working committee of the Uganda water and sanitation NGO network (UWASNET). (DSW1[12] – 18/9/02)

**M. M. Azhar Hossain** joined the self-help groups of disabled people through the CBR programme in Manikgonj, Bangladesh, and is now working as a leader of the local self-help group. (DSW01[03] – 12/9/02)

**Hazel Jones**, from Loughborough, UK, is the main researcher on the project on access for disabled people to water and sanitation at WEDC. Her background is in disability, having worked in special and inclusive education for disabled children, and community-based projects with disabled children and adults. Most of this experience was with Save the Children in Asia — mainly Thailand and Vietnam, and also former Soviet-bloc countries. (DSW1[02] – 12/9/02)

**Donatilla Kanimba** from Rwanda has been blind since childhood. She grew up in Kenya, but now works in Rwanda as Executive Secretary of the organisation of the blind. She is also in charge of the international relations in the Federation of Associations and Centres for Persons with Disabilities. (DSW1[04] – 12/9/02)

**Inge Komardjaja**, from Bandung, Indonesia, is a woman with a physical impairment. She is a government official, working with the Research Institute for Human Settlements, Department of Settlements and Regional Infrastructures. She has a PhD in planning and urban development, and her interest in

disability started with a focus on gender, independent living, and the built environment. (DSW1[01] – 5/9/02)

**Badsha Mia** is a leader of the local self-help group in Narayangonj, Bangladesh, having joined the groups of disabled people through a CBR programme. (DSW01[03] – 12/9/02)

**Meshack Mndawe**, is a deaf staff member of the Office on the Status of Disabled Person in South Africa, Mpumalanga province. She is responsible for project-related matters affecting people with disabilities. (DSW1[11] – 16/9/02)

**Lena Nielsen**, works for Danish Women with Disabilities in Denmark. (DSW3[12] – 7/10/02)

**Md. Sharsur Rahman**, is a disabled Self-help Group Leader from Tangail, Bangladesh. He has experience of conducting surveys and programme assessments and of training and presenting on issues of disability, from a social perspective. (DSW01[03] – 12/9/02)

**Karen Rieff** works in the International Department of the Danish Council of Organizations of Disabled People. (DSW3[16] – 10/10/02)

**Md. Sahadat Sarwar**, from Mymensingh, Bangladesh, became an executive member of BPKS, an NGO working with disabled people. He has conducted community surveys in disability-related projects and worked to identify suitable job opportunities for disabled people. He is currently organising public awareness programmes in Gazipur. (DSW01[03] – 12/9/02)

**Ehsunul Ambia Suhad** has worked for several years as co-ordinator of the occupational therapy Diploma and BSc course, at the BHPI, CRP in Bangladesh. He has worked extensively with students, teachers and other professionals in the field of OT services. He is also Head of the Department of Occupational Therapy, managing the OT interventions in the institute and community. (DSW1[09] – 16/9/02)

**Muhammad Mushfiqul Wara** is the Research and Evaluation Officer for CRP. He has worked in a research study looking at the levels of community integration of people with spinal cord lesion in Bangladesh and is currently co-ordinating the participants for the WEDC e-conference of water and sanitation. (DSW01[03] – 12/9/02)