

Water supply and sanitation access and use by physically disabled people

Revised inception report

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Executive Summary

Introduction

This report has been produced at the end of Phase 1 of KaR (Knowledge and Research) project R8059: 'Water supply and sanitation access and use by physically disabled people'. The research is funded by the UK Department for International Development (DFID) and carried out by the Water, Engineering and Development Centre (WEDC) at Loughborough University, UK.

Background and rationale

There are an estimated 580 million disabled people in the world; two thirds live in low-income communities, and 70-80% in rural areas of the South. One in five of the poorest are estimated to be disabled. The only way most disabled people will ever access their basic human needs and rights is through mainstream services and programmes. But disabled women, men and children continue to be discriminated against and ignored by mainstream services and programmes. Poverty reduction programmes, universal primary education drives, and economic growth targets all need to include disabled people if they are to meet their objectives.

This project aims to provide tools that could mitigate the effects of poverty for disabled people and their families by: meeting basic needs; increasing self-reliance of individuals; and providing opportunities for the disabled person to contribute to the family and community.

Project description

Goal: To raise the well-being of the rural and urban poor through cost-effective improved water supply and sanitation.

Purpose: Improved 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.

Initial findings

Activities undertaken in Phase 1 (October 2001 – October 2002) include: literature review, development of field-work methodology, e-conference, networking, selection of research team and advisory panel. Key findings were:

Lack of relevant information: Very little literature was found related to the research project, with a complete lack of information in some areas. Most of the information focuses on difficulties of access, rather than good practice.

Barriers to access – comprehensive approach needed: Barriers to disabled people's access include not only individual limitations, but more importantly environmental factors – physical, social, attitudinal, and institutional. To address only selected barriers is likely to prove ineffective. A 'comprehensive' approach is advocated as the most effective and sustainable.

Gap between policy and practice: Human rights based disability legislation and policies are increasingly widespread, but in practice this appears to have resulted in only limited improvements in disabled people's lives.

Key role of disabled people: Consultation with and involvement of disabled people are crucial in all issues that concern them, and have been shown to improve both effectiveness and sustainability of projects.

Gender: Many disabled women and girls suffer triple discrimination, for being female, disabled and poor. They are often neglected both by programmes for women and children, and by those aimed at disabled people. Community-based disability approaches have been criticised for increasing the work-load of women and excluding them from earning opportunities.

Project planning - implications for Phase 2:

Target audience: will be broadened to include domestic water and sanitation strategy planners and service providers. It will also aim to provide links with initiatives working towards social and institutional change.

Need for continuing collection of relevant information for the duration of the project.

Project scope has been clarified as: focusing on the family context; outputs will aim to be relevant to disabled people globally, and to organisations responsible for providing them with water and sanitation services. The project will include: children and adults with limitations in physical functioning and activity *for whatever reason*; access in terms of the means of disabled people entering and using facilities, but not aids and adaptations to do with general mobility; rural and peri-urban communities in low-and middle-income countries, and in economic transition.

Key role of disabled people: The project will continue to involve representatives of disabled people at different stages in the research planning and implementation: field work, data analysis, and dissemination of outputs.

Gender: Every effort will be made to ensure that the needs of disabled women and men are considered and addressed, by consulting women as well as men. The disabled person will be considered in the overall family context, and include the needs of carers to reduce time and effort spent on 'caring' tasks.

Review of project purpose and outputs

As a result of the broadened target audience, a significant increase in work is now proposed in terms of range of project outputs. This is not expected to significantly affect the length of time required or cost of data collection, but is likely to increase the time required for writing up and dissemination, and may have cost implications for this phase. This will be reviewed more fully when the dissemination proposal is submitted in September 2003.

Further and wider support for the project will be gained by on-going dissemination of information and interim outputs, and consultation on outputs with relevant organisations.

The first two countries to be visited are Uganda and Bangladesh. Further locations will be identified shortly. Criteria for selection of field-visits and a framework for data collection have been developed. These will be adapted in collaboration with local partners to suit each individual country context.

Monitoring and evaluation

No change is needed to the measurable indicators and means of verification which are detailed in the log-frame. A detailed dissemination proposal will be submitted nine months after the start of Phase 2, i.e. September 2003, according to the project contract. This will be based on WEDC's dissemination strategy.

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Glossary

AD	assistive device
BOND	British Overseas NGOs for Development
CBR	community-based rehabilitation
CRP	Centre for the Rehabilitation of the Paralysed
D&DWG	Disability and Development Working Group
DFID	Department for International Development
DHT	Disability & Healthcare Technology
DPO	Disabled people's organisation
GO	Government organisation
IDDC	International Disability and Development Consortium
IWGDD	International Working Group on Disability and Development
KAR	Knowledge and Research
NGO	Non-governmental organisation
OT	occupational therapist
PDF	Portable document format
QA	quality assurance
UN	United Nations
UN Standard Rules	United Nations Standard Rules on the Equalization of Opportunities for Disabled Persons
WEDC	The Water, Engineering and Development Centre
WHO	World Health Organization

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1. Introduction

This report has been produced at the end of phase one of KaR (Knowledge and Research) project R8059: '**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 at the Water, Engineering and Development Centre (WEDC), Loughborough University, UK, together with collaborators in the UK and in Bangladesh.

The project webpage is

<http://www.lboro.ac.uk/wedc/projects/auwsfpdp/index.htm>

1.1 Background and rationale

There are an estimated 580 million disabled people in the world. Two thirds live in low-income communities of the South (Miles, 1999), of whom 70-80% live in rural areas (Hadiwigeno, 1999). The number of disabled people is increasing, because of such factors as an ageing population, and the impact of violent conflict (World Bank, 2001).

Nevertheless, disabled women, men and children continue to be discriminated against, excluded by society, and generally ignored by mainstream services and development programmes (Seeley, 2001; Singleton et al, 2001; UN, 2002). As many as one in five of the poorest people in the South are disabled (Elwan, 1999), which means that almost every poor family is affected in some way by disability.

For the majority of disabled people in low-income communities, their human rights to life, food, water and shelter are a daily struggle. The only way disabled people will ever access these basic needs, and thus an acceptable quality of life, is through mainstream services and programmes. According to the WHO, only 1-2% of disabled people in low-income communities receive the rehabilitative services they need (May-Teerink, 1999).

The exclusion of disabled people has an impact on their families and communities, in both human and economic terms. Poverty reduction programmes, universal primary education drives, and economic growth targets all need to include disabled people if they are to meet their objectives (Stubbs, 2002).

1.2 Impact on Millennium Development Goals

This project will aim to provide tools that could mitigate the effects of poverty for disabled people and their families by:

- Meeting basic needs, without which a person often cannot begin to get access to other rights.
- Offering the opportunity for increased self-reliance of the individual, thus freeing up more time for carers to spend on more productive activities.
- Providing choices and opportunities for the disabled person to contribute to the family and community.

1.3 Report format

This format of this report is based on the Guidance Contents List specified in Annex C of the project contract.

The report aims to follow visual accessibility guidelines as recommended by the Loughborough University Disability and Additional Needs Service. Alternative formats (large print, Braille) may be available on request.

2. Project description

2.1 Goal

To raise the well-being of the rural and urban poor through cost-effective improved water supply and sanitation.

2.2 Purpose

Improved 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.

2.3 Outputs

1. Review of published data on access to and use of the domestic water cycle by physically disabled people.
2. Inception report.
3. Revised dissemination proposals.
4. Guidelines and manual for maximising access to and use of the domestic water cycle by disabled people and their families from low-income communities published and disseminated.
5. Case studies showing the successful use of the options promoted in the guidelines published and disseminated.
6. Publication of articles promoting project outputs, in various media, particularly those focussing on or seen by low income communities.

Issues 1 and 2 have been addressed during the inception phase.

2.4 Contract amendments

The project was signed by DFID on 16.10.01. A proposal with revised bar chart and budget was submitted in January 2002. This was because of difficulties and delays in recruiting the principal researcher. A revised contract has not yet been received.

Additional minor revisions to the bar chart were submitted in September 2002, as a result of the principal researcher starting in post one month later than anticipated. This has no impact on budget. The bar chart in Appendix II is based on the September 2002 revision.

3. Project outputs and activities

3.1 Phase 1 purpose

The purpose of Phase 1 has been to establish whether or not there is a need for the planned research, to verify that it will not duplicate existing efforts, to identify existing knowledge and practice that can be built on, to highlight gaps in information and practice, and to select countries for field visits.

3.2 Phase 1 outputs

These have been completed according to the revised project time-frame. See Appendix III for the Output to Purpose summary report.

3.3 Planned activities

All the planned activities of Phase 1 have been completed, apart from selection of third and fourth locations for field-visits.

3.3.1 Literature review

A desk-based review of current knowledge and best practice has been completed. Methodology involved searches of electronic databases, a call for information circulated globally through electronic networks to potential informants and collaborators, including:

- British Overseas NGOs for Development (BOND), especially Disability and Development Working Group (D&DWG) members and their networks.
- International Disability and Development Consortium (IDDC) members and their networks.
- International Working Group on Disability and Development (IWGDD) members.
- disabled people's organisations (DPOs) in low-income countries.
- UN agencies.
- Water and sanitation networks, discussion lists and electronic bulletin boards.

This enabled both published and unpublished literature, responses to the call for information from practitioners in the field and disabled people to be included in the review. A copy of the literature review accompanies this report and is available in PDF format on the project website.

The main findings of the literature review were:

- a. Lack of available information.
- b. Obstacles faced by disabled people include not only their individual limitations, but equally external barriers - physical, social and institutional.
- c. Clarification of project scope and definitions.
- d. Gap between legislation/policy and practice.
- e. Lack of appropriate resources and information.
- f. Key role of disabled people in all issues that affect them.
- g. Disability and poverty.
- h. Relevance of independence.
- i. Gender analysis.
- j. Assumption of stakeholder support.

These have been combined with findings from other Phase 1 activities and discussed in more detail in Section 4.

3.3.2 *Field visit locations identified*

Bangladesh and Uganda were identified as the first two field-visit locations. Subsequent locations are still under discussion, with Cambodia and South Africa strong possibilities.

3.3.3 *Field-work methodology*

Criteria for selection of field-visits and a framework for data collection have been developed. These will be adapted in collaboration with local partners to suit each individual country context (described in Section 4.3.4).

3.3.4 *Electronic conference*

A four-week electronic (e-mail) conference on Disability, Water and Sanitation was held between 9.9.02 and 4.10.02. The purpose was to provide a forum for participants to share information, experience and views on issues related to disabled people's access and use of water and sanitation facilities. The full synthesis report (Lewis et al, 2002) accompanies this report, and can also be accessed on the project website. Archived e-conference contributions can also be viewed on www.jiscmail.ac.uk/lists/dws.html.

Key conclusions included:

- Lack of appropriate water and sanitation facilities in low-income communities.
- Attitudes of others can inhibit access to facilities: need for awareness-raising about disability and access.

- Imported solutions often inappropriate, need for locally appropriate solutions.
- Lack of availability or sharing of knowledge and information in suitable formats for different users: need to produce/disseminate guidance documents.
- Need to strengthen participation of disabled people in planning, implementation and evaluation processes.
- Disability and accessibility issues need to be taken on board by everyone involved in watsan work, in every sector, at all stages.

3.3.5 Workshop at annual WEDC Conference 2002

The workshop took place in Kolkata on 22.11.02 after the close of the conference. See Appendix IV for workshop notes. The small number of participants meant that it was inappropriate to draw conclusions from the session, but key issues discussed included:

- How to present the disability and accessibility issue, so as to appeal more effectively to watsan service providers,
 - use of language,
 - promote technical problem-solving angle,
 - use of appropriate imagery.
- Issue of choice of technologies – how to present available options: need for demonstration/case examples that others can learn from.
- Need to understand whole family context – community development approaches in common use could incorporate disability issues.
- Need to consider technologies suitable for different contexts.

3.3.6 Phase 1 Inception Report prepared

Once approved, this report will be available in PDF format on the project webpage: <http://www.lboro.ac.uk/wedc/projects/auwsfpdp/index.htm> or directly from WEDC.

3.4 Other activities

3.4.1 Networking

Dissemination of information about the project, and a call for information (in English and French) have been circulated globally through electronic networks, to potential informants and collaborators, including: BOND D&DWG members and their networks, IDDC members and their networks, IWGDD members, DPOs in low-income countries, UN agencies, water and sanitation networks, electronic discussion lists and bulletins.

This enabled both published and unpublished information to be included in the literature review, and a database of contacts – specialists, key informants and potential collaborators to be established.

An e-mail discussion list was set up for the purpose of conducting the e-conference and remains active for the sharing of information on issues related to Disability Water and Sanitation. www.jiscmail.ac.uk/lists/dws.html .

3.4.2 Selection of research team and Advisory Panel

The Advisory Panel has been set up to support the research team in achieving the project purpose, and ensure that outputs are of an appropriate quality to meet the needs of the main stakeholders. Membership comprises representatives of relevant sectors. Two Panel meetings have been held together with frequent consultation via phone and e-mail. See Section 5.4 for further discussion, Appendix IV for a list of members, and Appendix V for minutes of the two meetings.

3.4.3 Learning from other KAR projects

Where possible, there has been discussion and networking with researchers working on other DFID research (KAR) projects, including Disability and Healthcare Technology (DHT) research, research within WEDC, and others. The most relevant have included:

R8016: Enhanced accessibility for people with disabilities living in urban areas. Purpose: to improve the mobility of the rural and urban poor for meeting their livelihood needs (Venter et al, 2002).

R7386: Designing water and sanitation projects to meet demand – the engineer's role (Deverill et al, 2002)

R7129: Practical guide to mainstreaming gender in water projects

R6575: Gender issues in the management of water projects

KAR DHT: Disability poverty and technology (DHT, 2002)

Urban Housing and access for disabled people (unable to obtain information).

3.4.4 Dissemination of interim findings

Articles describing project progress have been published in DFID 'Water' newsletter, and in Occupational Therapy News, and a technical paper submitted to Municipal Engineer for a forthcoming issue focusing on social inclusion.

4. Phase 1 findings

4.1 Available information

A wealth of information was found about access issues for disabled people in high-income and urban areas, including access to water and sanitation facilities, but most was irrelevant to low-income communities. There is a limited but growing body of literature about the problems faced by disabled people in low-income communities and approaches to service provision. Only a small proportion specifically mentions water and sanitation issues. Relevant information was found mostly related to activities of toileting, hygiene and self care, with only a few references to household activities using water. Virtually no information was found for a number of subject areas, namely: access and usability of natural water sources, wells, hand-pumps, tap-stands or rainwater collection systems; transportation, storage of, and access to stored water; and accessibility of household refuse disposal systems.

Most information tended to focus on the difficulties faced by disabled people, with only a few examples found that illustrated good practice. These often lacked detail. Information from practitioners in the field has been some of the most valuable, but again often lacked detail that has been difficult to follow up in the time available.

Box 1. Unpublished accounts of good practice

Zimbabwe: 'When I was in Zimbabwe in 1993 we visited a group of disabled women in an area two hours drive to the east of Bulawayo who had spent several years collecting money to build their own well, as the non-disabled women of their area charged them large sums for rides on donkeys and would not help them anyway. They got the full amount of money while we were there and they were overjoyed and quite determined to charge non-disabled people for the privilege of using their well! They were going to build it in a place that would serve several villages/communities and were going to share a donkey and other means of transport.' (Hurst, 2002)

Bangladesh: 'One interesting example is of disabled people in Chittagong, Bangladesh who have become agents of change for the entire village. For example becoming the liaison with water non-government organisations (NGOs) to arrange access for the village, and not just for people with disabilities and their families.' (Van der Kroft, 2002)

4.2 Barriers to access and participation: comprehensive approach

A widely-used framework for analysis which underpins much current research and practice is the 'social model' of disability, which locates the problems faced by disabled people as barriers in society and the environment. Together

with WHO's recently revised International Classification of Functioning Disability and Health (WHO, 2001), these have proved useful in identifying factors that hinder disabled people's access and use of water and sanitation facilities.

Barriers to disabled people's access and participation include:

- a) individual limitations
- b) environmental factors: physical, social/ attitudinal, institutional (services/systems/policies).

Box 2. Examples of barriers to access and participation

Individual: 'Physical weakness means that disabled people have to rely on stronger household members to collect water for them (Hollingsworth, 2001), or to wash themselves, their children, clothes, dishes, etc. at communal water places.' (Van der Kroft, 2002)

Physical: An account from Zambia describes a village where a community project was carried out to build latrines. 'Persons with disabilities did not benefit, they could not use them for they did not have a sitting pan and doors were too narrow for a wheelchair to enter. The same toilets were used as bathrooms ... I was talking to a woman with disability, who told me she bathed only at night and used the bushes as a toilet.' (Sachelo, 2002)

Social: 'In Bangladesh, because many community members believe that impairments are contagious or a punishment, disabled people may for example be prevented from sharing latrine facilities, which forces families to use unhygienic sanitation practices.' (CRP, 2002)

Institutional: 'In Bangladesh, there are no government services for physically disabled people to access water and sanitation facilities. Organizations working with disabled people do not consider accessing water sanitation as an issue. There is an NGO Forum for Water and Sanitation, which [comprises] NGOs and government organisations (GOs) working in water and sanitation, but it does not include disabled people in their programme.' (CRP, 2002)

A study of more than 165 US-based relief and development NGOs found that ... organisational strategic objectives make no reference to disabled people, most do not collect data on participation of disabled people in their programmes, and so cannot monitor the extent of their participation. Many respondents acknowledged that they think few or none do participate. (from Singleton et al, 2001)

These barriers need to be viewed holistically. To address only selected barriers, e.g. individual functional limitations, or barriers in the physical environment, whilst neglecting others, e.g. social and institutional barriers, is likely to provide at best only short-term benefits, and at worst prove ineffective. A 'comprehensive' approach to addressing barriers is widely advocated as the most effective and sustainable.

4.3 Project scope/definitions

A wide range of impairments, cultural perceptions of disability and geographic contexts were identified, all of which gave rise to different barriers to access. However, there appear to be some broad principles and processes involved in identifying and meeting the needs of disabled people, and of appropriate technology and equipment, that are globally applicable. Designs may need to be adapted to suit local cultural perceptions and social norms.

Particular issues that exacerbate access for disabled people arise in non family-based contexts, such as institutions, or situations of displacement through conflict or disaster.

4.4 Gap between policy and practice

It was clear from correspondence with individuals and organisations, contributions to the e-conference and review of the literature, that a human rights based legal and policy framework is essential for sustainable change in the lives of disabled people to occur. There is still some way to go in this area, but the issue is being addressed and progress is being made. It is evident that there is increased awareness of disability rights, and that legislation and policies based on the UN Standard Rules (UN, 1993) are increasingly widespread among governments and international agencies.

The main concern was the gap between legislation/policy and its translation into reality. Examples were found of countries with excellent legislation and policies on paper, but which have so far resulted in only limited improvements for disabled people in practice. The reasons cited for this include lack of understanding on the part of mainstream infrastructure and development implementers about how to include a disability perspective in their work, lack of training, lack of information on good practice, institutional discrimination, and local cultural perceptions.

Box 3. Gap between legislation and practice

In South Africa: '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 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.

'Measures were taken in the legislation to act against the discrimination of people with disabilities in terms of service delivery. 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. Equitable standards of practise should be implemented.' (Mndawe,

2002)

4.5 Lack of appropriate resources and information

The review findings indicate that practitioners interested in improving accessibility of water and sanitation facilities for disabled people experience firstly, a lack of easily obtainable information, and secondly, a lack of information that is in appropriate, user-friendly formats.

The few documents that are widely available, e.g. Werner (1987, 1998) and WHO materials, are aimed at disability-focused practitioners, not at the water and sanitation sector.

Box 4. Lack of information

Issues raised by 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.” (*From a discussion with WEDC engineers, reported in Lewis et al, 2002*)

4.6 Key role of disabled people

It is important to ensure that disabled people, their carers and communities, are involved not only as beneficiaries, but also take a leading role in all issues that concern them. Consultation at all stages in research planning, implementation and dissemination of findings has been shown to improve both the effectiveness and sustainability of projects.

Recent related research confirms that excluded groups, whether these are women, the poor, or disabled people, need not only practical changes, but also to be involved in decision-making (Deverill et al, 2002; Venter et al, 2002) for pragmatic as well as ideological reasons (DHT, 2002).

4.7 Disability and poverty

The overall goal of this research is to improve the well-being of the rural and urban poor. Review activities have confirmed the central premise of the project, i.e. that there is a strong link between disability and poverty. Disabled people are more likely to be poor, and a disproportionately high proportion of the poor are disabled.

4.8 Relevance of independence

One issue to emerge from the literature review is that self-reliance and independence are not primary concerns, or even perceived as relevant, in all cultures. This does not mean that self-reliance and independence may not be a concomitant outcome of achieving other personal goals, such as 'personal dignity' or 'contributing to the family'.

Needs assessments are widely used in services for disabled people, as a way of identifying personal goals and how these can be achieved, but it is not always clear whether issues related to water and sanitation are addressed.

4.9 Gender analysis

Disabled women and girls in low-income communities are doubly, if not triply discriminated against, for being female, disabled and poor. Programmes that target women and children often neglect disabled women and children, and elderly women, whilst those aimed at disabled people often prioritise adult males. DPOs are often dominated by disabled men, for whom the concerns of women and children and the rural disabled are low priority.

Many community-based approaches to disability have attracted criticism in their reliance on the voluntary labour of women family members and community workers. On the one hand this denies them opportunities to earn a living, and on the other, can relegate disability provision to a charitable activity, and absolve the State of its responsibilities.

4.10 Testing of assumption of stakeholder support

This is a new area of study for WEDC, and the project has had to start from scratch to build up a network of interested individuals and organisations. In spite of wide dissemination of information about the project, and call for information and interest, only a limited response has been received so far. The number of responses from people interested in learning from the research findings has been greater than those offering examples of good practice. Nevertheless, a small but enthusiastic network of organisations and individuals is interested in collaborating in the research, and this is expected to grow.

5. Project planning

5.1 Implications of findings on project scope, and key issues to be addressed in Phase 2

The implications of research findings from Phase 1, and how it is planned to address these during the rest of the project, are summarised in Table 1.

5.1.1 *Need for continuing data collection*

Efforts to identify and document relevant information need to continue for the duration of the project. This will be done through relevant networks (see Appendix VI for a list of dissemination networks), through observation, face-to-face communication on field visits, and any other opportunities for information sharing.

Information gaps will undoubtedly remain, indicating where further action-research is likely to be needed.

5.1.2 *Broadening of target audience*

The target audience will be broader than that envisaged in the original project contract. This focused largely on outputs aimed at organisations working with disabled people and their families, concerned with aids and techniques that provide individual solutions. These organisations, however, have limited responsibility and influence on the factors which determine access to water supply and sanitation for physically disabled people, in particular for the inaccessible physical infrastructure and social and institutional factors which have been identified as major barriers (section 3.3.2).

Therefore a more 'comprehensive' approach is needed which will necessitate broadening the target audience for project outputs. The project will investigate the ways in which the needs of disabled people are considered by water and sanitation service providers, and identify the kind of support needed – information, materials, etc. to enable them to do so more effectively, and for planners and decision-makers responsible for the development of domestic water and sanitation-related strategy. Outputs will also aim to provide links with initiatives working towards social and institutional change.

Table 1: Issues raised during Phase 1

Issue	How the project will address the issue	In original proposal	Added at inception phase	Comments
Lack of information on good practice.	Need to continue collecting information by: <ul style="list-style-type: none"> • Reviewing literature. • Documenting information found during field-work. 	✓ ✓		The assumption (which is proving to be true) is that information exists although neither easily available or even written down. Outputs will be based on existing examples.
Barriers to water and sanitation in physical environment .	Include domestic watsan service providers and strategy developers as part of target audience by: <ul style="list-style-type: none"> • Including representative on Advisory Panel. • Include watsan specialists in planning, consultations, and as resource persons as appropriate during field-work. 		✓ ✓	Because of budgetary and time constraints, <i>additional</i> activities focusing on this target group will not be undertaken.
Institutional barriers among watsan strategy developers and service providers.	Target watsan strategy developers and service providers as part of dissemination strategy.		✓	
Lack of understanding of disability issues among watsan strategy developers and service providers.	Take opportunities to raise understanding about disability among watsan providers, through e.g. disability content in MSc training, workshops at conferences, seminars, etc. Outputs to include lay-person's guide to disability issues.	✓	✓	
Social barriers to participation of disabled people in watsan related activities.	Outputs to include: <ul style="list-style-type: none"> • list of agencies working towards social and institutional change. • case studies that could be used by agencies working on disability 'sensitisation' for role play, group-work, etc. Dissemination strategy to include agencies working	✓	✓ ✓	A wide range of lobbying and advocacy activities already exist, which this project should not replicate, but ensure that outputs are produced that can feed into.

	towards social and institutional change.			
Gap between policy/legislation and practical implementation.	<p>Outputs to include guidelines on strategy development based on action-research framework of learning from pilot projects.</p> <p>Consultation/participation of watsan decision-makers in local field-work.</p> <p>On-going dissemination strategy to include watsan decision-makers.</p>	<p>✓</p> <p>✓</p>	<p>✓</p>	Major issue identified not of rights-based legislation, where progress is being made, but of difficulty of putting legislation into practice.
Lack of available appropriate practical information /examples.	<p>Outputs will provide information/examples of accessible designs in appropriate formats aimed at:</p> <ul style="list-style-type: none"> • disability practitioners. • watsan service providers. 	<p>✓</p>	<p>✓</p>	
Key role of disabled people in issues that affect them.	<p>Increase involvement and consultation with disabled people at all stages in research.</p> <p>Outputs to include guidelines on consultation with disabled people and their families at all stages in project cycle, and service provision.</p>	<p>✓</p>	<p>✓</p> <p>✓</p>	Role of disabled people has increased compared to original proposal.
Issue of relevance of goal of self-reliance in the South.	Outputs will provide examples of good practice, including assistive devices that help increase independence.	<p>✓</p>	<p>✓</p>	Focus not on total self-reliance, but on enabling disabled person to make a contribution to family/community, in line with local social norms.
Double discrimination against disabled women and girls, and elderly disabled.	<p>Ensure disabled women and the elderly are represented/ consulted throughout research, especially in field-work.</p> <p>Ensure concerns of female carers are given due consideration during field-work.</p> <p>Outputs to address issues related to disabled women, children, the elderly and female carers both throughout text and in separate section.</p>		<p>✓</p> <p>✓</p> <p>✓</p>	

5.1.3 Project definitions

Discussion during the first Advisory Panel meeting provided the main input to defining the project scope.

- *Family context*

The focus of the research is on the family household context. Where the household uses communal facilities, e.g. water source, latrines, waste disposal, these will also be included.

Many of the outputs are likely to be equally applicable in non-family-based contexts, such as institutions, conflicts, and disasters. The scope for wider application will be considered in the outputs, but the particular and unique issues that arise from each of these specific contexts are beyond the scope of this project, and will not be addressed.

- *Global relevance*

Outputs will aim to be relevant to disabled people globally. A broad, process-based framework will be applied, in such a way as to encourage the development of local solutions and adaptations.

Outputs will aim to achieve a balance between the local and the universal, by presenting generic examples of appropriate technology and equipment, as a useful basis for identifying local solutions. By contrast, specific examples of local adaptations and their uses will also be documented, to encourage local experimentation.

- *Physical disability*

For the purposes of this research, people who experience limitations in physical functioning and activity *for whatever reason* are included. The cause may vary: a physical impairment, or visual impairment resulting in difficulty finding one's way around, or old age resulting in physical weakness.

Outputs will apply to children, adults and elderly people with learning difficulties/mental impairment, brain injury or dementia, but will focus on addressing the physical manifestation of limitations, and any systems or technologies that could help minimise their impact on people's lives and livelihoods. It will not include methodologies to address mental or cognitive functioning. Wherever applicable, reference will be made to relevant resources and materials.

- *Access/accessibility*

This will include the possible means of disabled people entering and using the facilities in the course of the domestic water cycle. Structural adaptation and design of basic fittings and buildings, aids and equipment specifically devised to provide access and use of the domestic water cycle will be included. Aids and adaptations to do with general mobility, e.g. ramps, dropped kerbs, wheelchairs, crutches, splints, etc. will not be included. Outputs that advocate a holistic needs assessment to accessibility, however, will inevitably need to highlight the importance of smooth paths or road surface, for example, and refer to relevant literature.

Not only increased self-reliance will be addressed, but also issues such as increased dignity (e.g. privacy, cleanliness), hygiene, safety, and effort and time-saving. Access and use will be addressed in the context of the whole family, which might mean for example, savings in time or effort for a carer.

The Advisory Panel emphasised these physical constraints and possible aids to overcome them. In addition the project will consider institutional constraints to improving access.

- *Financial accessibility*

This will not be addressed directly. For example, solutions to the problem of a disabled person having to buy water because they cannot fetch it themselves, would aim to provide options to assist the person to fetch their own water, rather than address income generation.

The project will attempt to provide sufficient detail for users to determine the local cost implications of the provision of different designs and technologies.

- *Low-income communities*

This includes rural and peri-urban communities in both low-and middle-income countries, and countries in economic transition.

5.1.4 Appropriate information

The research is designed to collect and synthesise the kind of information that practitioners will find useful. The research team will ideally be multi-sectoral, to reflect the different sectors to be targeted, i.e. community workers, engineers, therapists, disabled people, etc. Field-testing by collaborators from different sectors will be used to determine appropriate format, language, and whether local versions of outputs are needed.

5.1.5 Key role of disabled people

The original research proposal identifies a role for disabled people primarily as beneficiaries, who would provide the required information, and then receive appropriate assistance.

Since the goal of this research is to improve the well-being of disabled people, the process of the research has been revised to contribute to this. The project is exploring ways to strengthen links with disabled people's organisations in low-income countries, especially those selected for field-work. It is also consulting and involving representatives of disabled people at different stages in the research planning and implementation: field work, data analysis, and dissemination of outputs.

The project will also produce information to guide planners and practitioners in consultation and collaboration with disabled people throughout project cycle, whether at national level, e.g. with DPOs, or at local level with disabled community members and their families.

5.1.6 Poverty and independence

In the light of the literature review, the project will not assume that personal independence is a primary motivation for all, nor that the greatest impact on family well-being is always through economic improvement. Aspirations other than personal independence, such as self-esteem, improved health, etc. may be of greater concern, and the disabled person and their family may need support to identify their own priority concerns and aims.

A broad-based needs assessment is not part of the project remit. The project will, however, consider what information might help those responsible for carrying out such an assessment, to address issues of access to water and sanitation as part of that assessment.

5.1.7 Gender perspective

A gender perspective is being applied. Every effort will be made to ensure that the needs of disabled women and men, including girls and boys and the elderly, are all considered and addressed, and that increased work-loads are not laid unquestioningly on female family members.

Consultation will include women as well as men, and young people and older people. The needs of the disabled person will be considered in the overall

family context, including the needs of male, female, and child carers to reduce time spent on 'caring' tasks, or to make those tasks less onerous.

5.1.8 Relevance of research to advocacy

It is important to understand the strategic role of this project in relation to policy development. There is a strong body of evidence to indicate that organisations advocating effectively on rights and access to services tend to take a multi-track approach. Whether DPOs, parents' organisations or other NGOs, practical grassroots implementation provides lessons that feed into and inform advocacy work.

In common with a number of bilateral and international development organisations, DFID's support for inclusion of disability issues in mainstream development is clearly stated in its 'Disability, Poverty and Development' issues paper (DFID, 2000). In order for this policy to be put into practice, however, information is needed about examples of effective practical implementation that can be disseminated. This project will make this kind of information available in various formats, so giving interested organisations the opportunity to put ideas into practice locally, and thus provide material for influencing their own governments and service providers.

Box 5. Practical implementation informs policy development

Some DPO projects are operated independently of government. The National DPO of the Philippines, KAMPI, runs Stimulation and Therapeutic Activity Centres, to provide assistive devices and training for independence for disabled children (Ilagan, 1998). The Bangladeshi DPO Proti-bandhi Kallyan Somity implements a wide range of activities, including education, medical support, awareness campaigns, job placement, and home-based therapy (Carew, 2002).

Elsewhere, DPOs collaborate with government in implementing community-based rehabilitation programmes. The Zanzibar Association of Disabled People collaborates with the Ministry of Social Welfare (Coleridge, 1993). In the Solomon Islands, the Disabled Persons Rehabilitation Association collaborates with the Ministry of Health and Medical Services (Williams, 1995).

All these and many other DPOs also work at a national level to lobby and influence government on rights and services for disabled people (Hossain, 1997, Seeley, 2001). The link between practical implementation and influencing governments is made – DPOs need to initiate programmes that will inform governments and local authorities on the importance of providing accessible facilities (Sachelo, 2002)

(Jones et al, 2002)

5.2 Review of project purpose and outputs

Various minor changes are proposed in the sections below, subject to DFID approval.

5.2.1 Purpose

The project purpose has been amended. The target audience has been broadened to include 'domestic water and sanitation service providers and strategy planners'. This now reads: 'Improved knowledge and use of affordable aids, methodologies and structures by organisations and individuals who assist physically disabled people and their families, and by domestic water and sanitation service providers and strategy planners in low income communities, to maximise their access to and use of the domestic water cycle.' The reasons for this have been outlined in Sections 3.3.2 and 4.1.1.

5.2.2 Outputs

Content of future outputs has been clarified, for details see Table 2. Increasing the diversity of the target audience presents a challenge, and outputs as specified in the project log-frame (Appendix I), no. 4 in particular, will need to be targeted to suit their differing needs. Table 2 also suggests the kind of information that is likely to be needed by different target groups.

The final format of outputs will be presented at the dissemination planning phase, based on feedback from field-testing of draft outputs.

In view of the slow response from water and sanitation professionals to date, particular attention will be paid to raising interest in project outputs among this target group through the research process itself. Information on the development of strategy aimed at domestic water and sanitation strategic planners will also be included in the outputs.

5.2.3 Activities

The logical framework stays largely the same, with a few adjustments and clarifications as follows (see Appendix I).

- Activity 3. Methodologies for field work - this has been reworded slightly to reflect more accurately the need for a participatory methodology and to avoid using the word 'evaluation' which can often imply a right/wrong judgement. This now reads: 'Methodologies for field work developed including criteria for inclusion and framework for data collection.'

- Workshop at WEDC Conference moved from Phase 1 to Phase 2, because of the late timing of the conference.
- Activity 7: the word 'evaluate' has been replaced by 'document and analyse', so the purpose of visits now reads: 'to document and analyse' current best practice and field test guidelines.'

All activities will aim to include members of the newly introduced target group – water and sanitation providers and strategic planners, as appropriate. For budgetary reasons, additional activities specifically focusing on this additional target group will not be undertaken.

5.2.4 Work-plan for remainder of project

A significant increase in work is now proposed (See Table 1). This will broaden the focus of data to be collected, but is not envisaged to affect the length of time required for data collection. The increased range of outputs proposed is however likely to increase the length of time required for writing up and dissemination.

5.2.5 Budget

As can be seen from Table 1, the project is proposing to considerably expand its remit. An assessment of the additional work suggests that it will have few financial implications for the data collection phase. However the increased range of outputs required may have cost implications for the writing up and dissemination phases. This will be reviewed more fully when the dissemination proposal is submitted in September 2003.

5.3 Description of methodology for remainder of project

5.3.1 Data collection

The primary source of new data will be field-visits, but literature will continue to be reviewed, and steps taken to expand the research network.

5.3.1.1 Field-visits

Purpose

The purpose of the field-work is to gain a better understanding of the ways in which disabled people access watsan services and of the interactions between the institutions providing these services and disabled people, and to collate examples of good practice in improving access and use by disabled

Table 2: Proposed content of outputs and different target groups

Content	Target group					
	<i>Disabled people & families</i>	<i>DPOs</i>	<i>social/ health/ community workers</i>	<i>domestic watsan service providers</i>	<i>domestic watsan strategy planners</i>	<i>Agencies working on attitude change</i>
a) Designs of personal assistive devices that contribute to independence.	✓	✓	✓			
b) Advice on working with disabled people and their families in assessment of needs and selection of solutions.	✓	✓	✓			
c) Case studies illustrating impact of ADs, accessible facilities, etc. on disabled person and family.	✓	✓	✓	✓	✓	✓
d) Designs for accessible watsan facilities, including materials, costs, etc.	✓	✓	✓	✓	✓	
e) How service providers could include /respond to disability issues, including initial community consultation through to monitoring and evaluation, including consulting disabled people and their families.		✓	✓	✓	✓	✓
f) Case studies illustrating watsan projects that specifically include disabled people – impact on disabled person/ family/community; roles & responsibilities of each sector.	✓	✓	✓	✓	✓	✓
g) Guidelines for development of strategy for accessible watsan services.		✓		✓	✓	✓
h) List of relevant resources and organisations working in support of watsan for disabled people.	✓	✓	✓	✓	✓	✓
i) Issues related to specific groups – disabled women, girls and boys, elderly people, those with specific impairments, and carers (especially female) included throughout text, but also in separate sections.	✓	✓	✓	✓	✓	✓

people of domestic water and sanitation facilities. Examples will be sought that address the following areas:

- Designs of personal assistive devices that contribute to independence.
- Advice on approaches to working with disabled people and their families in assessment of needs and selection of solutions.
- Case studies illustrating the impact of assistive devices (ADs), accessible facilities, etc. on disabled person and their family.
- Design specifications for accessible watsan facilities, including materials and cost implications.
- How service providers could include /respond to disability issues, including initial community consultation through to monitoring and evaluation.
- Case studies illustrating watsan projects that specifically include disabled people – impact on disabled person/family/ community; roles and responsibilities of different sectors.
- Guidelines for development of strategy for accessible watsan services.
- List of relevant resources and organisations working in support of watsan for disabled people.
- Issues related to specific groups – disabled women, girls and boys, elderly people, those with specific impairments, and carers (especially female).

Additional aims of field-work are

- to raise the profile of the project in low-income countries,
- to get input from local collaborators,
- to strengthen the capacity of local collaborators,
- to field-test ideas generated during previous field-work.

Sequence of activities

The first two field-work locations are Bangladesh and Uganda. In order to establish a relationship with potential local collaborators, short preparatory visits have been made to each by the principal researcher. Meetings were held with interested NGOs and GOs, to:

- introduce the research project and answer questions
- outline what the research will look at – criteria for inclusion of an example, identify potential field-work locations,
- agree specific objectives of field-work in that country.
- establish a local research network.

The networks comprise representation from different sectors – disabled people, water/public health engineering, development sector, education sector, community/health sector, including occupational therapy, etc.

Similar preparatory visits will also be made to the third and fourth field-work locations.

Following this preparatory visit, the main two-week visit will be undertaken to each country by the WEDC project team to carry out data collection, in association with local collaborators.

Visits will be made to family homes, communal facilities, residential institutions, orthopaedic workshops, local government offices, Ministries. DPOs

Interviews will be carried out with disabled women and men, girls and boys and their families, community leaders (as appropriate) watsan service providers and decision-makers, CBR, community, health and social workers, occupational therapists (OTs), DPOs.

Equipment will be catalogued, using photos, diagrams, sketches, measurements. Methodologies will be observed, described, photographed where appropriate.

To round up the field-work, summary meetings will be held, for all research participants, to provide an overview of the field-work, summary of information collected and main issues emerging. This will provide the opportunity for participants to see their contribution to the wider research, to get feedback on accuracy, gaps, and further issues to be addressed.

Role of local collaborators

Data collectors will be selected by the WEDC field-work team, according to their skills and experience, the type of data needed, who the interviewees are, and the range of target audiences envisaged.

Where local collaborators clearly lack the skills and experience needed to carry out data collection, other more appropriate roles and responsibilities will be identified for them. They may also act as advisors, liaison persons, informants providing background information on the development of a facility/project, and translators/interpreters.

Local collaborators will also carry out a co-ordination role, both in preparation for and during the field-work. This will involve:

- Identifying and communicating with local collaborators,
- Organising meetings, venues, and logistics,
- Liaising between UK-based team and local collaborators, including responding to and passing on queries, receiving and circulating information.

The role of the local disability adviser (see section 5.4 for rationale), will be to advise the research team on the local disability-related context - legislation, economic social and cultural issues, to provide a link with relevant local networks and contacts, and to contribute to analysis of data collected.

Data collection methodology

A common framework for data collection (see Appendix V) will be used in all countries, but *the way* it is used is likely to vary from one country to another. This will be agreed at initial discussions with local researchers before starting field-work. Areas to be discussed include:

- appropriate field-visit locations.
- key informants (GO and NGO watsan planners and service providers, DPOs, etc).
- appropriate field-work methods, e.g. focus group discussions, semi-structured interviews, participatory research tools.
- formats for documentation, e.g. visual: photos, sketched diagrams, video; oral/aural: sound recording, written: case studies, tables of information, direct quotes.
- skills and experience of local participants and assign appropriate roles and responsibilities.
- Adapt data collection framework (see Appendix V) for local use.

Visit reports will be checked for accuracy with contact persons and informants before inclusion in the country report.

Selection of countries for field-work

Criteria for selection of field-work locations are

- Availability of *current* information about multiple examples of good practice on access for disabled people to water and sanitation.
- Commitment/interest from a local partner.
- Support/approval of a local DPO.
- Contribution to a diversity of cultural and geographic contexts.
- Post-conflict country with problems resulting from land-mines.

Because of the difficulty in identifying examples, the third and fourth field-work locations have not yet been finalised, although Cambodia, South Africa and Kenya are possibilities. It is expected that through continued networking and dissemination about the project, further information will emerge to be able to finalise locations.

5.3.2 Analysis

The project team will analyse the field data, in the light of the literature review and other Phase 1 findings, to identify both common findings and also any unexpected results. These will be compiled and discussed for their relevance to different target groups, including policy-makers.

5.3.3 Field-testing

In the second and subsequent field-study countries, feedback will be sought on ideas generated in previous countries. This could include designs of assistive devices (ADs), accessible facilities, approaches to implementation by water service providers, community development workers, etc. Depending on the context, these will be discussed on visits to families and projects to get feedback on their applicability in that situation. This will help gain an understanding of the universality and adaptability of examples collated.

Field-testing of draft materials will be carried out through Advisory Panel members, collaborating partners, institutions and their networks. Also further agencies who have expressed interest in the project, e.g. UN agencies, international and local NGOs.

Draft materials accompanied by a questionnaire will be circulated to in-country collaborators, and to a range of other organisations for feedback and comments. Agencies with decision-making responsibilities, e.g. Water Departments, those involved in practical implementation, whether GOs, NGOs, or DPOs will be targeted. Not only Asia and Africa will be included, but also Latin America and countries in transition.

5.3.4 Dissemination

A dissemination strategy will be produced in September 2003 according to the project contract. There will be periodic dissemination of progress briefings, up-dates, and interim outputs. All documents are available for download from the project website.

5.4 Review of project team, partners/collaborators and responsibilities

The following changes have been made to the project research team:

The health/hygiene specialist specified in the original contract is proposed to be replaced by a local disability adviser. This is because consultation with the Advisory Panel at the first meeting in July 2002 concluded that a health/hygiene specialist is not a priority for the project as it is now envisaged, but alternative skills will be needed. Instead, this budget will be used to employ a local in-country specialist disability adviser, preferably a disabled person, who has knowledge and understanding of the local context, and has networks and contacts for the research to draw on. This specialist will be identified prior to each field visit. This change has still to be agreed with DFID.

The findings of the inception phase indicate the need for the project to broaden its skills and knowledge base, in particular in the area of water and sanitation technologies, and in giving a service providers' perspective on the analysis of data and on outputs related to service provision. It is therefore proposed to include a further member on the team (CV is attached as Appendix X):

- Dr Sam Kayaga, WEDC Assistant Programme Manager, specialising in Maintenance Management, Water Utility Management, and Institutional Development issues for low- and middle-income countries.

The Advisory Panel comprises a range of specialists to complement this team, including representatives of disabled people, low income countries, disability and health communication, elderly people, occupational therapy, physiotherapy, water and sanitation provision.

Of the six original collaborators cited on the contract, three remain the same, but three further agencies have been brought on board. Change of personnel, and organisational priorities can account for this:

Original collaborators:

- The Centre for the Rehabilitation of the Paralysed (CRP), Bangladesh, is represented on the Advisory Panel, and is partner and co-ordinator of the Bangladesh data collection field visit.
- Healthlink Worldwide (Advisory Panel member), provides advice, contacts in low-income communities and information for the literature review. Member of the research team on one field-work location.
- The College of Occupational Therapists (Advisory Panel member), circulates information through its global network of OTs.

New collaborators:

- Helpage International (Advisory Panel member), contributed information to the literature review, provided contacts in developing countries, advice on research methodology.
- Oxfam-UK/Ireland Public Health Engineering Technical Team (Advisory Panel member) contributed information to the literature review, provided contacts in developing countries.
- A representative of a DPO from a local country network (Advisory Panel) provides information on relevance at community, practical advice on approaches to research, and opportunities for information dissemination. e.g. the second meeting was attended by a representative from Ugandan Association of Hidden Talents (HITS).

In addition, key collaborators for each country visit will be identified. In Uganda the Disability Prevention and Rehabilitation Section of the Ministry of Health was the key collaborator.

To date the Panel has met twice, in July and November 2002, at WEDC and Healthlink Worldwide in London. The main focus of discussion was around the scope of the research, strategies for networking and information dissemination, and the research process. The minutes are attached as Appendix V.

5.5 Quality Assurance for data collection

Quality assurance of the data collection is based on the following procedures:

- selection of appropriate collaborator organisations
- agreement on contractual arrangements with collaborators, including use of the project research framework,
- selection, training and monitoring of researchers by WEDC field-work team (see Section 6)
- payment for contribution will be output rather than time-based.
- Data collection format will be structured in such a way as to separate fact/findings from conclusions and opinions.

6. Monitoring, evaluation and uptake strategy

6.1 Description of activity, output and impact indicators

The measurable indicators and means of verification are detailed in the logical framework (Appendix I). There is no need for any changes to these.

Evaluation of impact has not been built in to this project, as this would need to take place at least a year after the end of the project, as the full impact of the project will not become apparent until after its completion. Impact indicators will need to be formulated.

6.1.1 Monitoring of field-work

6.1.1.1 Self-monitoring

Project managers will review on a daily basis through discussion and feedback from collaborators, the relevance of data collected, gaps, and adjust data collection framework and own approach accordingly.

6.1.1.2 Local researchers

It is important to promote capacity of local researchers, especially if they are disabled people, but the baseline capacity of local collaborators in this research is an unknown quantity, as the relationship with WEDC is entirely new. Data collectors will be selected according to the suitability of their skills.

During two-week field-work: WEDC field-work team will monitor the performance of local data collectors, to ensure that they meet the standards required, and that they are aware of these. Data collectors will be selected according to their skills and experience, data collection will be carried out initially by WEDC team, observed by local collaborators, followed by data collection carried out by local researchers, under supervision of WEDC team. Coaching on certain issues, (e.g. asking leading questions, rigid use of the data collection framework as a fixed questionnaire) will be provided and response observed. Corroboration by fellow data collectors on performance and accuracy of data collected will be needed where a language other than English is used.

After the two-week visit by the WEDC field-work team, continued data collection will be supported where needed. Data will be required in both written and photographic form (cameras will be provided for researchers to use) and will be cross-checked against each other.

6.1.2 Project monitoring

This is done through the Advisory Panel, and through half-yearly progress reports.

6.2 Dissemination and uptake strategy (including participation of stakeholders)

According to the project contract, a detailed dissemination proposal will be submitted nine months after the start of Phase 2.

This will be based on WEDC's dissemination strategy, and the pathways outlined in Appendix VIII.

Articles describing project progress have been published in DFID 'Water' newsletter and in Occupational Therapy News, and a technical paper submitted to Municipal Engineer for a forthcoming issue focusing on social inclusion.

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Appendix I: Revised logical framework

Revised Narrative summary	Measurable indicators	Means of verification	Important assumptions
Goal: (F1): Raise the well being of the rural and urban poor through cost effective improved water supply and sanitation.			
Purpose Improved knowledge and use of affordable aids, methodologies and structures by organisations and individuals who assist physically disabled people and their families, and by domestic water and sanitation service providers and strategy planners in low income communities, to maximise their access to and use of the domestic water cycle.	Monitoring tools within the guidelines. Project outputs effectively disseminated.	Post project evaluation (not included in this project)	The guidelines are used during the planning of assistance to disabled people and their families.
Outputs: 1. Inception report published. 2. Revised dissemination proposals published 3. Review of published data on access to and use of the domestic water cycle by the physically disabled. 4. Guidelines and manual for maximising access to and use of the domestic water cycle by disabled people and their families from low income communities published and disseminated. 5. Case studies showing the successful use of the options promoted in the guidelines published and disseminated. 6. Guidelines and manual promoted with key stakeholders and end users in selected countries in Africa and Asia. 7. Project outputs promoted through articles published in various media, particularly those focussing on or seen by low income communities.	Report delivered to DFID 9 months after recruitment of research team. Proposal delivered to DFID 9 months after start of Phase 2 100 copies of report printed at end of Phase 1 and disseminated 400 copies distributed to key stakeholders within one year of end of project 50 copies of each case study distributed to key stakeholders by end of project End of workshop evaluations Published articles appearing in media	Confirmed by DFID Confirmed by DFID Feedback from recipients Database of recipients Database of recipients Workshop proceedings Copies of media.	Local policies and practices allow the use of project outputs

Appendix II: Revised project workplan

KEY	Completed activities	
	Projected activities	

YEAR OF ACTIVITY (02/03)

ACTIVITY	Months												
	A	M	J	J	A	S	O	N	D	J	F	M	
Phase 1													
Literature review													
Constitute advisory panel, select collaborating organisations and experts													
Select locations for field visits													
Develop field-work methodology													
Electronic conference													
Workshop at WEDC conference													
Purchase field-work tools													
Advisory panel meetings													
Submit inception report													
Investigate and develop links with other related KAR projects													
Phase 2													
Advisory panel meetings													
Prepare for field visits													
Visit two countries in Asia/Africa to gather data for inclusion in guidelines													
Prepare and publish visit reports													
Prepare for second field visit to Africa													
Prepare and publish articles to promote project outputs													
Prepare draft guidelines and manual													

OVERSEAS TRAVEL	DURATION (DAYS)												
By project members to Europe	10						10						
By Research Associate (30 days) & 2 other project members (15 days each) to 2 countries in Asia or Asia													30
													30

YEAR OF ACTIVITY (03/4)

ACTIVITY	MONTH												
	A	M	J	J	A	S	O	N	D	J	F	M	
Prepare and publish visit reports	■												
Prepare for second field visits to Asia and Africa	■	■											
Second field visit to 2 countries in Asia & Africa to gather data and field test guidelines		■	■										
Prepare and publish visit reports			■	■									
Prepare and publish articles to promote project outputs	■	■	■	■	■	■	■	■					
Finalise contents of guidelines and manual	■	■	■	■	■	■	■	■					
Peer review guidelines					■	■	■						
Advisory panel meetings			■										
Revised proposal for dissemination phase						■							
Phase 3													
Guidelines technically edited, typeset and printed										■	■	■	■
Guidelines disseminated										■	■	■	■
Prepare, publish and deliver articles to promote project outputs										■	■	■	■

OVERSEAS TRAVEL	DURATION (DAYS)												
By project members to Europe	5												
By Research Associate(30 days) & 2 other project members (15 days each) to 2 countries in Asia & Africa		30											
		30											

YEAR OF ACTIVITY (2004/5)

ACTIVITY	MONTH												
	A	M	J	J	A	S	O	N	D	J	F	M	
Guidelines disseminated	■	■											
Prepare and publish articles to promote project outputs	■	■											

OVERSEAS TRAVEL	DURATION (DAYS)												
None													

Appendix III: Output to purpose summary report

OUTPUT TO PURPOSE SUMMARY REPORT					
Title: R8059: Water supply and sanitation access and use by physically disabled people		Country: UK	MISCODE:		
Report No. 2	Date: October 2002	Project start date: 11.11.2001	Stage of project: Phase 1		
		Project end date: 30.5.2004			
Project Framework					
Goal Statement: Raise the well-being of the rural and urban poor through cost effective improved water supply and sanitation					
Purpose Statement: Improved 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.					
Outputs: 1. Inception report published 2. Revised dissemination proposals published. 3. Review of published data on access to and use of the domestic water cycle by physically disabled people. 4. Guidelines and manual for maximising access to and use of the domestic water cycle by the physically disabled. 5. Case studies showing the successful use of the options promoted in the guidelines published and disseminated. 6. Guidelines and manual promoted with key stakeholders and end users in selected countries in Africa and Asia. 7. Project outputs promoted through articles published in media that focus particularly on low income communities.		OVI: 1. Report delivered to DFID 9 months after recruitment of research team. 2. Proposal delivered to DFID 9 months after start of Phase 2. 3. 100 copies of report printed at end of Phase 1 and disseminated. 4. 400 copies distributed to key stakeholders within 1 yr of end of project. 5. 50 copies of each study distributed to key stakeholders by end of project. 6. End of workshop evaluations 7. Published articles appearing in media		Progress: 1. In preparation, likely completion early Nov. 2. None 3. Submitted electronically to DFID, hard copies to follow early November. 4. None 5. None 6. None 7. Article prepared for DFID Water newsletter.	Recommendation/ action: None
Purpose: Improved 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 access to and use of the domestic water cycle.		OVI: Monitoring tools within the guidelines. Project outputs effectively disseminated.		Progress: None	Recommendation/ action: None

Appendix IV: Workshop at WEDC Conference

Disability issues in water and sanitation

Saturday 23rd November, 10am – 1pm

Participants:

Monir Alam Chowdhury	PRISM Bangladesh; Khulna waste management; environmental management; sociologist
Charles Kigono Macai	International Rescue Committee, Kenya, working with IDPs, installing pit latrines, hygiene promotion.
Pastor William Ghosal	Mother Child Survival Development Revolution, Vill & PO Nazasinhapur, Bazasat, 24 Pgs (N)
Anil Kumar Kayal	Raybari Social Welfare Society
Amar Krishna Nashar	Vill: Nalpukur, PO: Ghateswar, Dist – (3) 24 pgs (S)

Aims

To introduce a new project researching access and use of domestic water and sanitation facilities for physically disabled people.

To discuss and develop ideas about how best to support professionals in the design and delivery of water and sanitation infrastructure and services.

Questions to be considered

- Drawing on participants' own experience, consider the problems that may be faced in delivering inclusive services, and factors that contribute to success or failure.
- Identify and share information on approaches that have been used and found effective.
- Make suggestions as to what tools the project might need to develop, and how best to communicate them.

Background

A number of agencies now recognise that disability is a human rights and development issue. Should be addressed as an integral part of all development programmes – those targeted at people, should include disabled people.

DFID's Issues paper 'Disability, Poverty and Development' proposed a 'twin-track' approach : on the one hand projects focusing specifically on disabled people, and on the other, to ensure that all development and infrastructure projects address disability as an integral part.

However, not yet implemented in practice. Why?

Because of lack of information, experience, because engineers have not read the disability issues paper. Lack of information aimed at planners and implementers of these infrastructure projects.

Discussion

Appropriate images for rural areas important

Issue of choice and how to present available options.

Necessity of situation analysis and understanding whole family situation

- potential use of PRA tools
- community development approaches that could incorporate disability issues

How to appeal more effectively to water and sanitation service providers:

- Promote technical problem solving aspect
- Using images of exclusion – e.g. posters – v striking
- Compare desirable/undesirable, before and after photos
- Video

Target audience needs to include donors

UNHCR – policy? Minimum standards – need to be included in SPHERE guidelines

Strengths & weaknesses of separate sections for children/ specific groups – need to guard against seeing each group separately

Demonstration/examples needed

Cases of what has worked where

e.g. at refugee camp, have rehab centre, could provide range of examples for trying out based on culture and acceptability

Different contexts – where there are latrines, no latrines. E.g. in rural areas in India 50% of population do not use latrines. So accessible latrines inapplicable.

Case–study from Charles:

The husband of a staff member was hospitalised for a week, during which time he could not walk unaided. As the latrines at the hospital were inaccessible for those who can't walk, the staff member needed to be with her husband. She had to take a week off work. In a "spirit of humanity", the office kindly gave her the week off. Now Charles thinks that a more effective response in the long-term would have been to identify how the latrines could be made more accessible for non-ambulant patients!

Appendix V: Data collection – framework

Depending on the type of visit being carried out, the appropriate data collection framework will be used. (Each framework will be presented on a separate sheet.)

1 Household visit

1a Introduction

Name Age: under 20; 20 – 29; 30 – 39; 40 – 49; 50+
 M/F Job/profession
 Location /Address
 Contact details
 Impairment; functional limitations
 Relationship to disabled person/role in relation to facility

1b General Background

Context – geographic – rural/peri-urban/village/farm, flat/hilly dry/wet etc

1c Domestic water cycle

<i>Drawing water</i>	<i>Description</i> Accessibility features; dimensions, materials used, technology used.
<i>Transporting /storing water</i>	<i>Function? Does it function as envisaged?</i>
<i>Using water:</i> <ul style="list-style-type: none"> • Bathing/personal cleanliness • Laundry, food/ dish-washing • House cleaning • Drinking water • Disposing of waste water 	<i>Quality: Durability? Appropriate for level of wear and tear?</i> <i>Use: Who uses it? The person it's designed for? How easily?</i> Is it used regularly, more/less than it could? Why? Could it be made more accessible? How? Who else uses it? How easily? <i>Appropriateness:</i> Cost, affordability; who contributed what? Materials locally available or not? Cheaper options? Cultural acceptability Gender appropriateness Convenience; safety; privacy; comfort
<i>Sanitation</i> <ul style="list-style-type: none"> • Latrine access & use/ alternatives • Rubbish disposal 	<i>Suggestions</i> Problems, suggestions for improvements? <i>Impact</i> Difference made to disabled person Difference to other family members Any negative impact? <i>General applicability:</i>

	<p>Suitable for which physical limitations? Suitable for anyone else? Who else could use it? e.g. elderly, children Could it be used in a different context? Could it be adapted for other uses?</p>
<p>Process of provision of AD/ adaptation of facility Description of process. Who/ How initiated?</p> <p><i>Individual:</i> where idea from ? Who provided advice/ training Who made it happen? How?</p>	
<p><i>Institutional</i> Agencies/personnel involved How/whether disabled person or family involved in process/choice/ design Factors contributing to success. Obstacles to implementation? Whether/how overcome At what stage in project process was accessibility thought about? Why at that stage? Was that the optimum stage? Funding source? How sustainable? Why happened here rather than elsewhere? To do with policy, law, individuals, training, NGO pressure?</p> <p><i>Comments/recommendations</i> Could it be done differently Anyone else involved or should have been</p> <p><i>Role of community (where applicable)</i> View of community</p>	

2. Accessible facility

2a Introduction

Location
 Organisation involved (where applicable)
 Name of informant
 Position

2b General Background

Context – geographic – rural/peri-urban/village/farm, flat/hilly dry/wet etc

<p><i>Description</i> Accessibility features; dimensions, materials used, technology used.</p> <p><i>Function?</i> Does it function as envisaged?</p>
<p><i>Quality:</i> Durability? Appropriate for level of wear and tear?</p>
<p><i>Use:</i> Who uses it? The person it's designed for? How easily? Is it used regularly, more/less than it could? Why? Could it be made more accessible? How? Who else uses it? How easily?</p>

<p><i>Appropriateness:</i> Cost, affordability; who contributed what? Materials locally available or not? Cheaper options? Cultural acceptability Gender appropriateness Convenience; safety; privacy; comfort</p>
<p><i>Suggestions</i> Problems, suggestions for improvements?</p>
<p><i>Impact</i> Difference made to disabled person Difference to other family members Any negative impact?</p>
<p><i>General applicability:</i> Suitable for which physical limitations? Suitable for anyone else? Who else could use it? e.g. elderly, children Could it be used in a different context? Could it be adapted for other uses?</p>
<p>Institution/ process Description of process of implementation/ provision of facility Who/ How initiated?</p>
<p><i>Institutional</i> Agencies/personnel involved How/whether disabled person or family involved in process/choice/ design Factors contributing to success Obstacles to implementation? Whether/how overcome At what stage in project process was accessibility thought about? Why at that stage? Optimum stage? Funding source? How sustainable? Why has this happened here rather than elsewhere? To do with policy, law, individuals, training, NGO pressure?</p> <p><i>Comments/recommendations</i> Could it be done differently Anyone else involved or should have been</p> <p><i>Role of community</i> View of community</p>

3 Service providers/Structures

3a Introduction

Organisation involved (where applicable)

Name of informant

Position

Location

Context – geographic – rural/peri-urban/village/farm, flat/hilly dry/wet etc

Institution

Roles and responsibilities in service provision, including for disabled people
 Knowledge/understanding of interviewee of disability among service users – prevalence, current situation, needs, etc.

Knowledge/understanding prevalent in organisation

Legislation /policy - related to service provision for disabled people

Strengths, opportunities, weaknesses

Strategy/guidelines - current /envisaged

Progress/ constraints to strategy development

Implementation

Inclusion of disability issues - successes

How initiated? By whom?

At what stage was accessibility thought about? from outset, or later?

Why at that stage? Optimum stage?

Factors contributing to success

Constraints to implementation? Whether/how overcome

Role of community? View of community

Comments/recommendations

Funding – source? Sustainable? Comments/suggestions

Why has this happened here rather than elsewhere?

Is it to do with policy, law, individuals, training, NGO influence?

Opportunities/constraints to improving inclusion of disabled people:

Legal framework

Needs identification

Staff resources

Available knowledge/information on appropriate provision

Financial issues

Incentives/barriers to change

Appendix VI: Criteria for inclusion of examples in field-work

Criteria for inclusion of examples in field-work
<p>Accessible facilities, adaptations, equipment, (home-made or provided externally), or activities that have helped children and adults with physical impairments and limitations improve their access to water and sanitation-related activities.</p>
<p>Water and sanitation-related activities:</p> <p>Drawing and transporting water, domestic water storage, i.e. placing water into and taking it from a secondary source, such as a storage jar.</p> <p>Domestic bathing and laundry, household cleaning, grey water disposal.</p> <p>Sanitation - urination and defecation; household solid waste and excreta disposal.</p> <p>Communal facilities are to be included where domestic facilities may not be available, e.g. in informal settlements such as peri-urban slums.</p>
<p>Facilities:</p> <p>Water sources such as springs, wells, rivers, streams and ponds, hand-pumps, tap-stands (both public and private), and rainwater catchment tanks.</p> <p>Domestic laundry and bathing facilities,</p> <p>Solid waste and toilet facilities, both pedestal and squat, water-seal and non water-seal.</p>
<p>Physical: drawing/ transporting/storing water</p> <ul style="list-style-type: none"> • Water sources that have been designed to be accessible and easy to use by disabled /elderly people/children/pregnant women. • Home-made equipment or assistive devices to make collecting and transporting water easier for a disabled person. • Water storage facilities – jars, tanks, etc. that have been adapted for easy use by disabled people.
<p>Using water:</p> <ul style="list-style-type: none"> • Accessible bathing facilities • Assistive devices/equipment to make bathing and personal hygiene tasks – oneself or by a carer – easier. • Accessible laundry, food/dish washing facilities, or equipment - either bought or home-made - to make household tasks easier. • Drinking water – assistive devices.
<p>Latrines/toilet facilities</p> <ul style="list-style-type: none"> • Accessible latrines • Adaptations to latrines to make them more accessible for people with physical difficulties • Assistive devices/ equipment to make toileting easier – for disabled person, or for the carer. • Alternatives to latrines – ways that disabled people cope.
<p>Approaches:</p> <ul style="list-style-type: none"> • Examples of projects/initiatives where community-based approaches have been used at community level in consultation/ needs assessment, where disabled people have been included.

Appendix VII: Research team & Advisory Panel

Project core team

Project Manager – RA Reed, WEDC. Engineer with many years experience in water supply and sanitation in development and refugee situations.

Disabilities professional/social/community development worker – Hazel Jones (Research Associate) WEDC.

Dissemination Specialist – Dr Julie Woodfield, WEDC Specialist in knowledge management. (replaces D Saywell who is no longer available).

Occupational therapist – Ms Heather Payne, Disability Adviser, S Asia Regional Link Co-ordinator, Healthlink Worldwide, Cityside, 40 Adler St, London, E1 1EE.

Health/hygiene education specialist – no longer considered relevant, and it is suggested this should be replaced by:

Local disabled specialist adviser – to be identified prior to each field visit. (Subject to approval by DFID).

Water utility management, and institutional development specialist - Dr Sam Kayaga Assistant Programme Manager, WEDC.

Water supply and sanitation specialist for low-income communities - Peter Harvey, Assistant Programme Manager, WEDC

Advisory Panel members

Mr Andrew Bastable/Mr Daudi Bikaba, Public Health Engineering Technical team, Oxfam, UK.

Dr Carolyn Baylies, Senior lecturer in Sociology, Centre for Disability Studies, University of Leeds, LS2 9JT, UK.

Centre for the Rehabilitation of the Paralysed, Savar, Bangladesh: Mr AK Momin, Director; Mr Muhammad Mushfiqul Wara, Research and Evaluation Officer, Ms Valerie Taylor, Co-ordinator.

Ms Elly Macha, Tanzania DPO, at the time PhD student, Centre for Disability Studies, University of Leeds, LS2 9JT, UK.

Mr Adam Platt, Programmes Director, Helpage International, PO Box 32832, London, N1 9UZ, UK.

Ms Samantha Shann, British Association of Occupational Therapists, WFOT representative, Northumbria University, Occupational Therapy, Coach Lane Campus, Benton, Newcastle upon Tyne NE7 7XA, UK.

Ms Emi Yamazaki, Japan International Co-operation Agency, (at the time PhD student) Centre for Disability Studies, Leeds University, LS2 9JT, UK.

Representative of a DPO from a local country research network. (Second meeting was attended by Mr Elijah Musenyente, Chairman, Uganda Society for Hidden Talents (HITS), P.O. Box 7304, Kampala, Uganda).

Appendix VIII: Minutes of Advisory Panel meeting

No. 1: WEDC, 17th July 2002

Present:

Dr Carolyn Baylies	Leeds University
Ms Elly Macha	Disabled people's organisation, Tanzania
Ms Heather Payne	Healthlink Worldwide
Mr Adam Platt	Helpage International
Ms Samantha Shann	Occupational therapist
Ms Valerie Taylor	Centre for the Rehabilitation of the Paralysed
Ms Emi Yamazaki	Japan International Co-operation Agency
Project members:	
Mr Bob Reed	Programme Manager
Ms Hazel Jones	Assistant Programme Manager
Dr Julie Woodfield	Dissemination specialist

- 1 **Introductions** and briefing about WEDC.
- 2 **Background** to development of the project.
- 3 **Project overview:** aims and objectives, key outputs, methodology, as outlined on web-page www.lboro.ac.uk/wedc/projects/auwsfpdp/index.htm
The project needs to be seen in the context of DFID's recent Disability Poverty and Development Issues Paper, which stresses that the needs of disabled people are to be addressed through mainstream development projects, in particular those that address poverty reduction. Improving access to water and sanitation will increase opportunities for disabled people to be self-reliant and to contribute to the family, and reduce the burden of care of family members, and improve opportunities for earning income.
- 4 **Purpose of Advisory Panel.**
The draft TOR were referred to. The importance of the AP role was stressed, and that their views can have an influence on project development. Heather emphasised that the AP's role is advisory, but not decision-making, which lies with the project team. One addition to Responsibilities was agreed: to advise on the process of the research. (See final TOR attached).
- 5 **Overview of activities and progress** to date were presented.
Phase 1 is currently under way, with the following focus:
Networking: awareness of the project among potential collaborators, resource persons, overseas contacts.
Advisory Panel established.
Literature review under way.
Information and calls for information have been circulated among both disability networks and water and sanitation networks. The response has been limited so far. A number of expressions of interest have been received, but fewer contributions of information. The majority of contributions focus on problems experienced by disabled people, and only a minority give examples of good practice, from Uganda and Bangladesh.

A link has been made with KAR project on accessible transport.

The key issue was the limited information forthcoming from low-income countries. To address this, further contact details were suggested:

- Information about a wind-powered well project in Tanzania (Elly will provide)
- to contact ICACBR (in Canada) directly
- re-send memo to OTs via Samantha
- more personal follow-up to DPOs in country
- contact training institutes with diploma/degree students carrying out research projects (e.g. Design, OT, PT...)
- Cambodia contacts (Emi)

It was also acknowledged that desk-based inquiry has limitations, and that getting out and talking to people will be more productive.

6 Project scope

For purposes of project feasibility, it was felt necessary to define more clearly the scope of the project. The following areas were discussed:

a People with physical disabilities:

Agreed to be defined as: people who experience limitations in physical functioning for whatever reason. The cause may be a physical impairment, or visual impairment resulting in difficulty getting around, or old age resulting in frailty and physical weakness.

It was agreed that the project would include disabled people of all ages, from children to elderly people. There was in-depth discussion in relation to elderly people, and the issue of dementia in particular, which causes functional limitations. It was agreed that the project will include this group, but would focus on addressing the physical manifestation of limitations in functioning, and any systems or technologies that could minimise their impact on people's lives and livelihoods. It will not include methodologies to address mental or cognitive functioning.

The same would apply across the age spectrum. Children with physical limitations as a result of learning difficulties/mental impairment will be included, but the project will address design solutions only, and not approaches to teaching children with difficulties understanding. Reference would however be made to relevant resources and materials.

Certain groups of end users, e.g. OTs, will have the professional skills to adapt the guidelines in ways appropriate to the needs of particular groups. It is important to involve carers, as elderly people are mostly cared for in the extended family (Elly).

Deaf people, even though they may have no physical limitations, need to be both included in the process and in the final outputs as appropriate, in order not to contribute to existing discrimination against them (Emi). Contact will be made with organisations of the Deaf in order to get input how this can best be done (Hazel).

b Access/accessibility

Was accepted to include usability and entering and exiting facilities. Issues of general mobility, getting to and from a facility were discussed. It was accepted that the project cannot address construction of wheelchairs, or roads. Outputs that advocate a holistic needs assessment to accessibility will inevi-

tably need to highlight the importance of smooth paths or road surface, and refer to relevant literature.

Financial accessibility will not be addressed directly. e.g. solutions to a disabled person having to buy water because they cannot fetch it themselves, would aim to provide solutions to assist the person to fetch their own water, rather than address income generation

c Domestic water cycle:

The definition as presented in the project contract was accepted, although there was discussion about whether 'productivity' will be included. The point was made that many disabled people would feel an artificial distinction was being drawn between personal domestic use of water and commercial/productive use. Elly pointed out that many disabled women in rural Tanzania support themselves and their families with home vegetable plots. It was agreed that the process of discussion and negotiation with local partners will need to take a flexible approach to defining 'domestic use' - this will undoubtedly differ between countries and between rural and urban communities.

d Geographic scope:

It was agreed that it was advantageous to include both African and Asian countries and to be able to produce a tool that could be globally applicable. There are many issues that are globally relevant to people everywhere. A wider diversity of countries and environments are likely to result in outputs covering a diversity of scenarios and solutions

It was agreed that two countries could initially be decided as a focus of in-depth study visits, (e.g. Bangladesh and Uganda, based on responses received to date).

The outputs will need to emphasise the process of inclusion, involving disabled people in project planning and design, and provide not a blue-print, but examples of solutions only.

There is a project requirement to include a country with a high incidence of mine injury – Cambodia would be one possibility, especially as

7 Cultural aspects of disability.

Discussion of the relevance of Independent Living and interdependence in different cultures needs to be brought more to the fore in the literature review (Heather). The human rights/Standard Rules are globally applicable and therefore need to be emphasised more strongly than the social model of disability (Carolyn).

8 Process of field study visits

In order to make best use of limited field visit time, pre-visit preparation will be needed, communication with a variety of organisations in country, re project purpose, visit purpose, appropriate site visits, people to talk to.... This could be done either by a preliminary visit, or through email contact with a 'co-ordinating' body or individual in country.

Discussed the possibility of identifying partner organisations in countries that may be able to undertake some of the research in more depth than can be done through visits of specialists. E.g. in Bangladesh: CRP has research capability; Cambodia: Emi will be based there with JICA from October 2002 and has useful contacts; HAI has a community programme.

9 Project specialists:

some have yet to be identified. In view of the broadening of emphasis of the project from that originally envisaged, it was agreed that Specialists with different areas of expertise from those stated in the project contract may need to be substituted as more relevant. For example, a specialist in disability awareness-raising or participatory methodology instead of health/hygiene.

10 Issues for future meetings:

Outputs: How far should this project go to ensure uptake and impact?
Mainstreaming outputs
Advisory Panel membership.

11 Date of next meeting:

early November, to be determined as soon as possible.

N.B. There was not enough time to discuss Outputs, but comments related to outputs were raised during the meeting. Useful tools that could be included in outputs:

Adam stressed the need for outputs promoting a holistic approach to needs assessment to accessibility. This will need to consider a wide range of factors, including economic factors, infrastructure and mobility needs, etc.

Decision flow diagrams/trees that help identify options and where solutions may be found – showing what the project's outputs will help with, and where people should go for other solutions.

Appendix VIIIb: Minutes of Advisory Panel meeting

No. 2: Healthlink Worldwide, 11th November 2002

1. Present

A K M Momin	CRP Bangladesh
Adam Platt.	Help Age International.
Bob Reed	WEDC
Hazel Jones	WEDC
Heather Payne	Healthlink Worldwide
Muhammed Mushfiqul Wara	CRP Bangladesh
Museniyente Elijah	Uganda Society of Hidden Talents

2. Approval of minutes of last meeting

Minutes of the meeting held on the 17th July 2002 were approved subject to the addition of the following text at the end of section 6.d: -Cambodia would be one possibility, especially as Emi will be posted there in October.

3. Matters arising

3.1 Contacts with possible sources of information

All the contacts suggested in the meeting were followed up but only one replied.

3.2 Advisory panel

It was noted that the advisory panel did not include a female with a disability. The point was acknowledged and the steps being taken to redress the balance described. Some aspects of the agreed project scope were clarified for new members of the panel.

4. Project briefing

4.1 Activities and outputs

Activities and outputs completed so far constitute the whole of Phase One of the project. This includes: establishment of a database of contacts to gather data and disseminate outputs; completion of a literature review of published and other available material; completion of an e-conference to supplement the literature review; and the completion and submission of an inception report.

4.2 Findings

The findings so far can be summarised as follows:

- a) The findings from the E conference confirmed those of the literature review.
- b) Published information on the core subject matter is very limited. There is much written on water and sanitation provision for disabled people in urban high-income communities, and the problems faced by disabled people in low income communities. Very little exists about good practice in low-income communities.
- c) The review of literature is not complete. Efforts must continue to find more through future contacts and activities.

- d) The need for field visits is justified. There is a limit to the quantity of data that can be collected as a desk study.
- e) The problem of access is not only an individual issue for disabled people. Often the main barriers are institutional and environmental. The project must expand its focus to address these areas. Therefore the target audience for the project should also include water supply and sanitation providers. There must also be a link with social and advocacy issues such that outputs and information collected can be used by organisations involved in such areas.
- f) Disabled people must play a full part in the implementation of the research and not be seen purely as beneficiaries.
- g) The establishment of a user group in Bangladesh to participate and contribute to the e-conference was a positive step in involving beneficiaries in the project and raising the profile of WATSAN problems. The methodology should be disseminated and promoted as a positive approach to producing multiple benefits from research.

5. Issues for the project to address

5.1 Examples of good practice

A number of ideas were mentioned to gather more examples of good practice. These included:

- Keep the E-discussion list open and encourage readers to continue to use it. There were some comments that the short duration of the e-conference did not allow sufficient time for participants to discuss the topics with a wider audience and feed back inputs.
- Establish national discussion groups in various countries to act as fora for data collection and dissemination.
- Involve schools and other groups to draw pictures of known problems and local solution.
- View contacts on Healthlink database.
- Make more use of personal communications on the phone rather than relying on letters and email.
- Devise activities by which participants get more direct benefit from being involved.
- Improve the readability and look of the outputs.
- Place articles in future Healthlink and Garnet newsletters.
- Make use of the Disabled Day in Uganda in December.
- Prepare a simple flyer to promote the project.
- Document practices in Uganda and Bangladesh and publish in 'Disability World' to promote further interest.
- Place articles in 'Drumbeat', 'HIFnet', WFOT bulletin and similar Physio document.
- Promote the project at the WEDC conference.

5.2 Field visits

It now looks like the first field visit will be to Uganda in late January, followed by Bangladesh in March. Preparatory visits will be made to Uganda in December and Bangladesh in November.

Further countries under consideration are Cambodia and South Africa (Momin has links but also try the President's Office)

The importance of face-to-face meetings with disabled people in their homes was emphasised, as was the need to find ways of involving disabled groups in the data collection.

Research methodology

Disabled people must be involved in the research but need not necessarily participate in the data collection. The main role is decision making.

The research team must be able to address engineering problems as well as personal and family problems.

The research and data collection process should be defined during the preparatory visit.

Outputs

The following were suggested as possible outputs:

- Suggestions for making public services more accessible.
- Ideas for technologies and techniques for improving independence.
- Tools for assessing WATSAN needs.
- Advocacy tools based on the research.

The project should set up a matrix of target audiences and needs to determine the number and types of outputs required. This could be developed during the field visits to get the views of collaborators.

Specialist advisers

A disabled specialist should replace the health and hygiene education specialist mentioned in the project proposal. This could be one person for the whole project, but it may be better to recruit someone in each of the countries visited. They would advise the team on the situation of disabled people locally, provide links with local organisations and disabled people, and could accompany the research team on field visits and give a disabled person perspective to the observations, technologies and techniques considered.

A researcher from a local academic institution would also be an asset but it was appreciated that it may be difficult to find someone with an appropriate interest.

5.3 Next meeting

The date, time and location of the next meeting were not fixed. It will be in about six months time and focus on project dissemination.

Appendix IX: Dissemination Pathways

Organisation/Project	Pathway
Research project	www.lboro.ac.uk/wedc/auwsfpdp/ e-mail discussion list dws@jiscmail.ac.uk
Disability focused	
<i>Disability focused</i>	
Healthlink Worldwide (HLWW)	Source International Information Support Centre www.asksource.info/ Disability Dialogue (+ regional editions)
Healthlink supported local networks	
Disability Information & Communication Theme Group	e-mail list (Short memo)
Exchange (managed by HLWW)	Mailing list ; lunchtime meetings
KAR Disability & Healthcare Technology	Website www.kar-dht.org under 'Links' Newsletter
International Disability and Development Consortium	www.iddc.org.uk/ Mailing list
CBR Forum	http://dag.virtualave.net/cbrforum.htm
BOND Disability and Development Working Group	e-mail list ; Meetings
Disability Awareness in Action	Newsletter
DisabilityWorld e-zine	http://www.disabilityworld.org/
Dutch Coalition on Disability and Development	http://www.dcdd.nl/
Danish Disability Council	http://www.disability.dk/
Asia Pacific Disability Rehabilitation Journal	article
Water and sanitation / infrastructure fora	
KAR Water	www.dfid-kar-water.net/home.shtml Newsletter
Source WatSan News	Website
Gender Water Alliance	Website
The Water Page	Website
GARNET (last updated 12/01)	Website
Water-and-san-applied-research	Discussion list
Sanitation connection	www.sanicon.net/index.php3 Under 'Human development and poverty' Urban-environmental-health discussion list
Municipal Engineer	Journal article
Community development	
Child rights information network	e-mail list ; Newsletter

Appendix X: Curriculum Vitae

Dr. Sam Kayaga
Water, Engineering and Development Centre
Loughborough University

FULL NAME:

Sam Mbaziira KAYAGA

DATE OF BIRTH:

21 October 1958

ADDRESS:

WEDC
Loughborough University
Loughborough
Leicestershire LE11 3TU UK

NATIONALITY:

Ugandan

MARITAL STATUS:

Married

EDUCATION AND QUALIFICATIONS:

2002 PhD, Department of Civil and Building Engineering, Loughborough University
1995 MSc in Water and Waste Engineering, Loughborough University
1982 BSc in Mechanical Engineering, Makerere University, Kampala - Uganda

MEMBERSHIP OF PROFESSIONAL BODIES:

Member of Uganda Institution of Professional Engineers
Registered Engineer under Engineer's Registration Board, Uganda

OTHER MEMBERSHIP

Non-Executive Director and Senior Partner for WSS Services (Uganda) Ltd, a water and sanitation consulting firm based in Uganda, involved, among other activities, in managing water and sanitation services of seven small towns of Uganda on a management contract with local municipal councils.

LANGUAGES:

- Runyakitara (Ugandan native)
- Luganda (Ugandan native)
- English
- Swahili

SPECIALIZATION AND RESEARCH INTERESTS:

- Urban water and sanitation utility management
- Rural water supply and sanitation services
- Operation and maintenance management in water and sanitation institutions
- Institutional development for water and sanitation agencies in low- and middle-income countries
- Accelerating services to the urban poor

- Capacity building for water and sanitation institutions in low- and middle-income countries
- Public Private Partnerships for water and sanitation services

PRESENT APPOINTMENT:

2002 Assistant Programme Manager/Research Associate at Loughborough University: appointed for research and capacity building in Institutional Development and Utility Management Unit of Water Engineering and Development Centre; Delivery of some modules on the MSc programmes at Water Engineering and Development Centre (WEDC).

PREVIOUS APPOINTMENTS:

2000-2002 Chief Engineer, Operation & Maintenance, National Water & Sewerage Corporation (NWSC), Uganda; in charge of operation and maintenance in 12 operational towns of NWSC, Uganda

1995-2000 Principal Engineer Maintenance, National Water & Sewerage Corporation, Uganda; in charge of preventive and corrective maintenance activities in 12 operational towns of NWSC, Uganda

1987-1994 Area Manager/Engineer for National Water & Sewerage Corporation, Uganda for the service towns of Entebbe, Masaka, Tororo, Mbale and Jinja , all in Uganda.

1984-1987 Water/Sewerage Engineer for National Water & Sewerage Corporation, Uganda for the service Town of Jinja in Uganda.

1983-1984 Assistant Engineer, Owen Falls Power Station, Uganda Electricity Board, Uganda.

1982-83 Trainee Engineer, Sugar Corporation of Uganda Ltd, Uganda

RESEARCH EXPERIENCE:

2002...ongoing **Uganda and India:** Institutional and community management aspects of the research project on improved risk assessment and management in piped water supply

2002...ongoing **Uganda, South Africa & India:** Formation of a learning and teaching network: matching the skills and capacities of engineers with the demand of employers

1999- 2002 **Uganda and South Africa:** Price and Service Differentiation of Utility Water/Sanitation Services for the Benefit of All, especially the Urban Poor.

2001 **Uganda:** Research on “Customer Relations Management in Urban Water Utilities”. I contributed to a DFID position paper entitled ‘Developing Customer Relations Management for Urban Water and Sanitation Authorities’, and carried out a case study on ‘Improvement on Customer Relations Management: The Case of National Water & Sewerage Corporation, Kampala – Uganda’

2000 – 2001 **Uganda:** Research on establishing dialogue with water consumers living in low-income settlements of the urban centres. Consequently, I wrote a case study paper entitled “Improving Dialogue between a Water Utility and Low-Income Consumers: Testing PREPP Methodology in Kampala, Uganda”.

1997-2001 **Uganda:** Ph.D. research on institutional strengthening of urban water utilities. The research topic was “The influence of consumer perceptions on cost recovery”.

1998 **Kenya and Tanzania:** Benchmarking Water Utilities in Eastern Africa: Working visit to the water utilities of Dar-Es-Salaam Water Authority (Tanzania); National Water Conservation and Pipeline Authority, Mombasa (Kenya); and Nairobi City Council (Kenya).

- 1996** **Zambia, Zimbabwe, Botswana and South Africa:** Research for Best Practices in Water Utilities in Southern Africa: working visit to the water utilities of Lusaka Water and Sewerage Corporation; City Council of Harare; Water Utilities Corporation, Botswana; North West Water Supply Authority, South Africa; Umgeni Water; Durban Metro Water and Waste (South Africa)
- 1995** **Uganda:** M.Sc. Research Dissertation on the research topic, “Marketing of water/sanitation services: NWSC (Uganda), a case study”

RECENT CONSULTANCY WORK

- 2002...ongoing** **Uganda:** In-country Training Programme for capacity building of district/project water and sanitation engineers all over the country
- 2000 – 2001** **Uganda, Kenya, Tanzania, Lesotho, Congo Brazzaville and Togo:** Regional consultant for Water Utility Partnership (WUP) for Africa, for phase 1 of a project on “Management of water utilities and reduction of unaccounted-for-water” Phase 1. Activities carried out in this consultancy included participation in and contribution to the development and pretesting of the performance audit manual; carrying out audits in the towns of Entebbe (Uganda), Mwanza (Tanzania), Maseru (Lesotho) and Kisumu (Kenya); compiling performance audit reports; organising and participating in the dissemination workshop in Kisumu (Kenya); and participating in the phase one evaluation workshop.
- 2000- 2001** **Uganda and South Africa:** Consultant for Institutional Management Options Group, based at IHE, Delft, The Netherlands, for carrying out case studies on “National Government Incentives Given to Urban Water Utilities for Serving the Urban Poor”. Case studies carried out in Uganda and South Africa.
- 1998 – 2002** **Uganda:** Water and sanitation services consultant for Uganda Christian University, Mukono, Uganda.

RECENT PUBLICATIONS

1. Kayaga, S.M. (2002), Is urban water sector reform in Uganda pro-poor? 28th WEDC Conference Proceedings – Kolkata, India; WEDC, Loughborough University, UK
2. Kayaga, S.M. (2002), The Influence of Customer Perceptions of Urban Utility Water Services on Bill Payment Behaviour: Findings from Uganda; PhD thesis, Loughborough University, UK
3. Coates S., Sanson, K.R., & Kayaga, S.M., (20001), PREPP – Improving Utility Watsan Services to Low-income Consumers, 27th WEDC Conference Proceedings – Lusaka, Zambia; WEDC, Loughborough University, UK
4. Kayaga S.M. & Franceys R.W. (20001) Incentives to Serve the Urban Poor: South Africa’s Case, 27th WEDC Conference Proceedings – Lusaka, Zambia; WEDC, Loughborough University, UK
5. Kayaga S M & Onek H O (1998), Public-Private Partnership: NWSC, Uganda; 24th WEDC Conference Proceedings – Islamabad, Pakistan; John Pickford (Editor); WEDC, Loughborough University, UK
6. Kayaga Sam & Franceys Richard (1998), Market Orientation for Water Utilities; 24th WEDC Conference Proceedings – Islamabad, Pakistan; John Pickford (Editor); WEDC, Loughborough University, UK
7. Kayaga S M & Onek H O, (1997), Water Utility Research: NWSC, Uganda; 23rd WEDC Conference Proceedings - Durban, South Africa; John Pickford (Editor); WEDC, Loughborough University, UK

8. Kayaga Sam (1997), Why pay for water? Footsteps No 30, March 1997; Isabel Carter (Editor); Tear Fund, UK
9. Kayaga M Sam (1997), Marketing of Watsan Services: NWSC Uganda; Institutional Development Series; Richard Franceys (Series Editor); WEDC, Loughborough University, UK. (ISBN 0 906055 52 0)