Water supply and sanitation access and use by physically disabled people

A literature review

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Contents

List of acronyms

AD	assistive device
ADL	activities of daily living
AT	assistive technology
basti	slum area in Bangladesh
BOND	British Overseas NGOs for Development
CBR	community-based rehabilitation
CIL	Centre for integrated/independent living
CRP	Centre for the Rehabilitation of the Paralysed, Bangladesh
DET	Disability Equality Training
DFID	Department for International Development (UK)
DPO	disabled people's organisation
GO	government organisation
IBR	institution-based rehabilitation`
IDDC	International Disability and Development Consortium
IL	independent/integrated living
ILO	International Labour Organisation
INGO	International non-government organisation
NGO	non-government organisation
OT	occupational therapist
PLA	participatory learning in action
PRA	participatory rural/rapid appraisal
UN	United Nations
UNCRC	United Nations Convention on the Rights of the Child
UNDP	United Nations Development Programme
UNESCAP	United Nations Economic and Social Commission for Asia and the Pacific
UNHCR	United Nations High Commissioner for Refugees
WHO	World Health Organisation

1. Introduction

1.1 Scope of the review

A review was undertaken of both published and unpublished literature from all over the world. Formal published literature was found through searches of 20 library databases, 14 web-based journals and information networks, 10 United Nations (UN) websites, and over 40 further websites of funders, bilateral and non-government agencies.

A call for information was circulated through British Overseas NGOs for Development (BOND) Disability and Development Working Group members, international NGOs (INGOs), several mailing lists, announcements on three e-mail discussion lists, on electronic bulletins, via UN agencies and disabled people's organisations (DPOs).

1.2 Background context

Disabled people exist in every community of the world. It is estimated that of 580 million disabled people, two thirds live in low-income countries of the South (Miles, 1999), of whom 70-80% live in rural areas (Hadiwigeno, 1999). Moreover, the number of disabled people is increasing, because of a steadily 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, 2001a; Singleton et al, 2001; UN, 2002). As many as one in five of the poorest people in the South are disabled (Elwan, 1999), which would mean that almost every poor family in the South is affected in some way by disability. When it comes to education, a mere 2% of disabled children have access to schools.

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).

1.2.1 Human rights

Disabled people have traditionally been seen as 'cases' to be 'cured' by medical interventions, failing which they are referred to welfare departments for 'care' (Philpott and McLaren, 1997). Or they are considered in need of 'protection' and charitable handouts (Ho, 1997), a paternalism which creates dependence (Jayasooria et al, 1997). This has begun to change over the last few decades however, as governments and international institutions now widely recognise that disability is both a human rights and development issue (DFID, 2000a; UN, 2002; UNESCAP 1995a; World Bank, 2001).

An important international instrument to promote the rights of disabled people is the UN Standard Rules for the Equalisation of Opportunities for Disabled Persons (UN, 1993). Although not legally binding, the Standard Rules provide a globally recognised framework upon which governments can formulate rights-based disability legislation and policies. The International Year of Disabled Persons in 1982 was followed by the International Decade of Disabled Persons, which put disability rights issues firmly on the agenda of many countries. In recognition of the lack of progress made in the Asia Pacific region, however, the UN Economic and Social Commission for Asia and the Pacific (UNESCAP) followed this with an Asian and Pacific Decade from 1993 to 2002, and its own regionally relevant Agenda for Action (UNESCAP website). A second Asia Pacific Decade has now been agreed, to build on the achievements of the first. An African Decade is also now under way (Pan African Conference, 2002), and in the Middle East a decade is being proposed to the Arab League.

A further useful instrument which is legally binding on signatories is the UN Convention on the Rights of the Child (UNCRC), where 'all rights apply to all children without exception' (UNCRC, 1989, Article 2). The Convention can potentially provide a valuable framework to monitor the rights of disabled children (Jones, 2001a; Lansdown, 2001).

Current progress towards a UN Convention on the Rights of Disabled People received a boost in November 2001. A UN resolution established an Ad Hoc Committee which would 'consider proposals for a comprehensive and integral international convention to protect and promote the rights and dignity of persons with disabilities' (UN, 2001; Light, 2002a, 2002b).

1.2.2 The social model of disability

Disabled academics and activists have long rejected the traditional medical view of disability, i.e. that disabled people are abnormal, and need a cure or treatment in order to integrate into 'normal' society. Instead they promote a human rights approach, and a 'social model' of disability, which refers to:

'a complex system of economic and social constraints imposed on people with impairments by the organisation of society.' (Editors, *Disability, Handicap and Society*, 1993).

This analysis has influenced a number of international agencies, which now recognise that what prevents disabled people's participation includes not only individual limitations of disabled people, but also physical barriers in the environment, 'a complex of cultural, social and economic rules' (UNESCAP, 1995a) and 'societal barriers' (WHO, 2002).

WHO's new International Classification of Functioning, Disability and Health (ICF) has also incorporated this social perspective, and now provides a classification of health and health-related domains as follows:
- body functions and structures.
- activities, i.e. the ability to carry out a task or action.
- participation, i.e. the involvement in a life situation.

Environmental factors are also included in the analysis - the physical, social and attitudinal environment in which people live and conduct their lives (WHO, 2001).

1.2.3 Poverty and disability

It is widely acknowledged that disabled people are among the poorest of the poor (UN, 2002). Poverty is both a cause and a consequence of disability (ACP-EU Joint Parliamentary Assembly, 2001; DFID, 2001a; Doyal, 1983; Elwan, 1999; Krefting, 2001; Miles, 1999; Radda Barnen et al, 1998; Yeo, 2002). Poor people are more likely to experience a host of obstacles to health and well-being: inadequate nutrition, dirty drinking water, improper hygiene and sanitation, limited health services (including inadequate vaccination and harmful birth practices), accidents, dangerous working and living conditions, lack of information, war, conflict and disaster, HIV/AIDS (Bosch et al, 2001; May-Teerink, 1999; Miles, 1999; NORAD, 2002; Siriwardane, 1997; Unnikrishnan, 2002), All or any of these cause impairment. Poor people also have least access to the services which would minimise the impact of impairments, such

as timely medical intervention, access to assistive devices, or the benefits of mainstream development, such as good roads and public transport (Doyal, 1983; May-Teerink, 1999; Taunyane and Hirschowitz, 1995).

At the same time, disabled people are more likely to be poor as a result of isolation, lack of opportunities for education, employment, socialisation and political activity. The lost earning opportunities of carers also increases the burden on poor families (Helander, 1999). A poor child with an impairment is least likely to survive – in some low-income communities there may be as many as two disabled people missing for every one that survives infancy (Krefting and Krefting, 2002). Ninety per cent of disabled children will not survive beyond the age of 20 (Lansdown, 2001). Disabled people are also at particular risk of HIV/AIDS infection, as they lack access to health information and are least able to protect themselves (NORAD, 2002; Save the Children, 2000a).

1.2.4 Economics

There is a general lack of research into disability and economics (Elwan, 1999). Probably the most widely promulgated study, the Global Burden of Disease, attempted to assess the future economic impact of disease and disability, and produced a standard unit, the Disability Adjusted Life Year (DALY) as an assessment tool (Murray, 1996; Murray and Lopez, 1997). The DALY is highly controversial however, with critics branding it unethical, in its premise that the life of a disabled person is of less value than that of a non-disabled person (Arnesen and Nord, 1999), and fatally flawed (Metts, 2001), on the grounds that DALYs assume that a given impairment always has the same severity of impact, regardless of the context in which it occurs.

The costs to the family and community of excluding disabled people far outweigh the costs of including them (DFID, 2000; Stubbs, 2002). One estimate of GDP lost as a result of disability is between $1.3 and $1.9 trillion (Metts, 2000). The majority of disabled people could be included in programmes and services with only minor adjustments, and at the same time other vulnerable groups would benefit, such as elderly people, pregnant or nursing women, and young children, at 'minor additional cost'. Incorporating adjustments from the outset is more cost-effective than making (usually more expensive) changes as an afterthought (*ibid.*).

1.2.5 Mainstreaming

An increasing number of governments now include disability as a significant aspect of development assistance, including Norway (NORAD, 2002), Sweden (SIDA, 1999), the UK (DFID, 2000a) and US (USAID, 1997, 2000).

There are moves among a number of governments and policy-makers not only to implement projects specifically targeted at disabled people, but increasingly to ensure that the needs of disabled people are actively addressed in mainstream poverty reduction, education and health initiatives. Variously termed a 'comprehensive', 'integrated' or 'twin-track' approach (e.g. DFID, NORAD, Save the Children/UK, UNESCAP, World Bank), the emphasis varies, but strategies generally include:

1   A disability-focused approach, including:
   * Rehabilitation strategies focusing on individual disabled people, provision of assistive devices that meet specific daily living needs.
   * Vocational training and employment programmes.
   * Empowerment strategies, supporting organisations and groups of disabled people, or parents' of disabled children.

2   A 'mainstreaming' or 'inclusive' approach, including:
   * 'slight modifications' of mainstream programmes (Dudzik and McLeod, 2000), or specific components targeted at disabled people, e.g. architecture and design strategies that promote access to the built environment (NORAD, 2002; UNESCAP, 1995a).
   * ensuring that the needs of disabled people are 'automatically included in the planning, financing and implementation of mainstream development co-operation activities' (Seeley, 2001a).
   * promoting a social milieu that welcomes the participation of people with disabilities.

Such an inclusive approach should be taken if a project is 'disability relevant', i.e. if it 'addresses the well-being of all people and /or focuses on essential services' (Wiman, 2001, quoted in World Bank, 2002).

The recent UN International Plan of Action on Ageing (UN, 2002b) provides an example of mainstreaming in practice. A section focusing on 'older persons and disabilities' proposes a comprehensive range of actions, both disability-focused and inclusive.

All strategies stress the importance of full consultation with disabled people – 'Nothing about us without us' (Yeo, 2002). The path of gender in development provides a useful model for disability in development (DFID 2001a).

1.2.6 Disability in different cultures

Disability is not a fixed state that can be objectively measured, but its parameters vary from one culture or environment to another (Stubbs, 2002). People who in the North may be considered disabled because of learning difficulties for example, may, from the author's experience, go unnoticed in a rural community somewhere like Vietnam, where physical labour is more highly valued than literacy. In many African countries on the other hand, people with albinism are automatically considered disabled, and often highly stigmatised, whereas they tend not to be in the North.

Large numbers of disabled people in low-income communities are victims of prejudice, ignorance and superstition, and their rights routinely abused (Hurst, 1999). It is important to note however, that as in the North, a continuum of attitudes and behaviour exists, and that abuse of disabled people's rights is also widespread in the North (DAA, 2001). A growing body of literature indicates that many low-income communities can be more accepting of their disabled members than in the North (e.g. Ingstad and Whyte, 1995; Jones, 1999b; Kisanji, 1995a, 1995b; Miles and Hossain, 1999; Stubbs, 2002; Talle, 1995).

1.3 Problem statement

Whilst it is increasingly acknowledged that the needs of disabled people must be addressed by mainstream development initiatives, it is also recognised that this is not always easy to do. A gulf remains between rhetoric and reality (USAID, 2000; Stubbs, 2002), and few examples exist of how it has been implemented in practice.

The issue is characterised by a lack of information (Mulholland et al, 1998; Singleton et al, 2001) and economic research (Elwan, 1999), with disability largely ignored in development initiatives (Seeley, 2001; Stubbs, 2002). Where isolated attempts are being made to improve access for disabled people, practitioners find themselves unsupported, with 'inadequate information or data and virtually no co-ordination of activities' (Metts, 2000). UNESCAP (1995a, 1997) highlight the need for improved sharing of information on appropriate assistive devices, and for research on access in rural and peri-urban areas. Without this information sharing, further replication of good practice remains highly unlikely (Haque, 2002).

1.4 Purpose of research, review, methodology, limitations

This research project number R8059 is funded by the UK Department for International Development (DFID) as part of its Engineering Knowledge and Research (EngKAR) Programme. The purpose is to improve the knowledge and use of affordable aids, methodologies and structures by organisations and individuals that assist physically disabled people and their families living in low-income communities, to maximise their access to and use of the domestic water cycle.

The literature review is part of Phase one - the preparatory phase of the research. The aim is to gain an overview of available information and current practice in low-income communities, about accessibility of domestic water and sanitation facilities for physically disabled people, in order to identify:

- Topics already covered (documented and being addressed), which the project does not need to repeat.
- Information that could contribute to the research.
- Apparent gaps in information where further enquiry is needed.

Both published and unpublished literature have been reviewed, including personal communications from informants in low-income communities: NGOs, DPOs and professionals in health, engineering and development.

Methodology has been desk-based, including searches of library databases, researchers' own document collections, and email and postal communication with individuals in low-income communities.

1.5 Definitions of some concepts and terms used in this study

1.5.1 Physical disabilities

For the purposes of this research, we have included children and adults who *for whatever reason:*
a) cannot walk, and may use a wheelchair, trolley, or other mobility device.
b) can walk with difficulty, and need support from e.g. crutches, hand rail, or another person to lean on.
c) can walk, but experience other physical weakness or lack of co-ordination, such as weak or erratic grip, or limited arm/hand movements.

1.5.2 Domestic water cycle

This is deemed to include: drawing and transporting water, domestic water storage, i.e. placing water into and taking it from a secondary source; domestic bathing and laundry, household cleaning, grey water disposal, sanitation - urination and defecation; household solid waste and excreta disposal. Communal facilities are to be included where domestic facilities may not be available, e.g. in informal settlements such as peri-urban slums, if time permits.

Facilities to be looked at include point sources such as springs, wells, rivers, streams and ponds, hand-pumps, tap-stands (both public and private), and rainwater catchment tanks. Laundry, bathing facilities, solid waste and toilet facilities, both pedestal and squat, water-seal and non water-seal.

1.5.3 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 should be included. Aids and adaptations to do with general mobility, e.g. ramps, dropped kerbs, wheelchairs, crutches, splints, etc. are not included.

1.5.4 Low-income communities

This includes rural and peri-urban communities in both low-and middle-income countries, and countries in economic transition. This is because wide economic disparities exist in many middle-income countries, e.g. in many rural areas of South Africa (Taunyane et al, 1995).

1.6 Report structure and format

The report comprises three main sections. Chapters 1 and 2 introduce and examine the range of issues and barriers that prevent disabled people from accessing and using water and sanitation facilities. Chapters 3 to 5 present the available information on what can be done and how, to address these issues, and identify some of the relevant current debates. Chapter 6 draws together the key implications for this research: areas that are already well-documented, areas where there are gaps in information that need further research, and current trends and debates that the research needs to take into account.

The report is formatted according to visual accessibility guidelines of the Royal National Institute for the Blind, UK. Ariel 12pt has been used for the main text, with a ragged right margin. Alternative formats may be available on request.

2. Problems disabled people face

It is widely recognised that disabled people's participation in activities of daily life is limited not only by their individual impairments, but equally, if not more so, by external barriers - environmental, social and attitudinal (Barnes and Mercer, 1997; Craddock and McCormack, 2002; Editors, Disability Handicap and Society, 1993; Miles, 1999; Swain et al, 1993; UNESCAP, 1995a).

2.1 Individual limitations

The most detailed information in studies of problems faced by disabled people tends to be about the physical limitations of individuals. Ability/inability in carrying out activities of daily living (ADL) is a common focus. A study in Nepal of people with impairments resulting from leprosy found the most commonly affected activities included washing clothes and washing dishes, carrying water-pots, watering the land and pouring water (Van Brakel and Anderson, 1998). Mulholland et al (1998) studied a group of ten disabled women with physical impairments in India, with the aim of understanding their day-to-day mobility needs. Nine of the ten were able to access toilet and bathing facilities 'with varying degrees of difficulty', and they had difficulty fetching water, because of the distance involved and their difficulty in transporting objects.

Among a group of physically disabled children in Nepal, Boyce et al (2000) report limitations of functional activities such as mobility, household chores and self-care.

Pain is identified as a limiting factor in carrying out daily activities (*ibid.*), reported by 32.7% of 248 children in the sample group. Mulholland et al (1998) found that among a group of Indian women with physical impairments, pain in limbs or joints caused problems, and discomfort from the ground being too hot or cold on their hands or legs.

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

Among the elderly, functional limitations become increasingly common with age. Of a group of over 65 year olds studied in South Africa, 11% had difficulty washing, bathing or showering, and 5% had difficulty using the toilet (Taunyane and Hirschowitz, 1995).

Functional limitations can depend on cultural behavioural norms. In Asia, many household and personal activities are carried out at ground level, such as washing up, laundry and bathing (Mulholland et al, 1998). Elderly women with mobility problems find it difficult to participate in activities that are done in squatting, kneeling or sitting positions; sitting on a chair or bench would be more comfortable, but embarrassing (Komardjaja and Parker, 2001).

In Muslim and Hindu communities, the left hand is used for washing oneself after using the toilet instead of using toilet paper. Many disabled people may either need help to do this, or they have to cope in a culturally unacceptable way, i.e. by using the right hand (Van der Kroft, 2002). However well it is washed, the hand remains socially 'dirty' and 'should never be used for handling food, eating, shaking hands, etc.' (Ahmed and Rahman, 2000).

2.2 Barriers in physical infrastructure and environment

Physically disabled people face numerous difficulties in accessing both the natural rural environment and the built environment (Haque and Begum, *undated*; Kulkhanchit, 2002; Philpott and McLaren, 1997), which is 'so constructed that only a specific type of user can manoeuvre in it' (UNESCAP, 1995a).

2.2.1 Barriers to water sources

Access to natural water sources can be difficult. Lakes, ponds and rivers often have soft or rocky banks and sloping surfaces down to the water. These features impede access for those with mobility impairments and can also make approach surfaces more slippery and difficult. 'The most difficulty is getting access to water in the pond or river or lake [which is] muddy near by the village' (Mony, 2002).

Interviews with people with physical impairments in Bangladesh draw the conclusion that collecting water is a problem for anyone using assistive devices. For example, accessing tube wells presents obstacles to users of wheelchairs or trolleys (CRP, 2002). Some disabled interviewees said they had taps in their house but they cannot use them because the rooms are inaccessible for their wheelchair or trolley.

2.2.2 Barriers to transporting water

For transporting water, distance and terrain can be a barrier (Van der Kroft, 2002). Some people have to walk over 5km and for several hours (Sachelo, 2002), on hilly or sandy ground (Togonon, 2002), rugged or 'diverse' terrain - wet, muddy, sloping, with pits, drainage canals and rocks, made worse by the monsoon (Mulholland et al, 1998). No references were found to problems with storing or accessing water in the home.

2.2.3 Barriers to using sanitation facilities

Where built latrines are available, access needs of disabled people are rarely considered (Sachelo, 2002). Where toilets are raised above ground level, e.g. to allow room for composting bins below, or because of a high water table, access can be difficult for the disabled or elderly (UNEP, 2000). Squat toilet facilities are common in Asia and Africa. In the suburbs in Zambia, toilets have no sitting pans, which means people with impaired lower limbs cannot use them (Sachelo, 2002).

For children using wheelchairs in a Ugandan primary school, toilet access can be problematic. Kiwanuka (2002) reports that 'some latrines are a long distance from their hostel or home or class, and many do not have ramps. Some children have difficulty opening the doors to enter, closing while inside - the door locks are sometimes too high for them, space inside is limited to freely turn and transfer. Cleaning after use and washing hands is also hard, the taps seem to be too high. For those crawling they find the floor too dirty, yet they use bare hands at times when crawling.' Where a water source is not close by, the user may face the problem of how to carry water to the latrine for washing (Mulholland et al, 1998).

Inaccessibility can force disabled people into unhygienic and inappropriate practices (Ahsan, 2002; Sachelo, 2002). A disabled Bangladeshi man describes having to use a 'bush of bamboo' beside his house (OFI, 1998). An account from Zambia describes a village 'where a community project was carried out to build pit 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 – persons with disabilities could not use them. 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).

If the latrine is not accessible, disabled children may need to continue using 'nappies', or soil their clothes. This regular washing of both child

and laundry increases the burden on carers. In addition, disabled peo-ple risk being stigmatised and isolated both within the household and community if they cannot keep themselves clean up to community stan-dards (Van der Kroft, 2002).

2.2.4 Rural issues

Because of underdeveloped infrastructure, isolation and inaccessibility of most rural areas (Hanko, 1998; Siriwardane, 1997), compounded by security problems in some countries, e.g. Cambodia (Bonnet, 1997), the majority of people in rural low-income communities have very limited services (Bonnet, 1997), including often inadequate healthcare (Hanko, 1999). Thus living in a rural area makes it more difficult to access ap-propriate services, even where they exist, as in Australia (Gething, 1997), and has even been found to increase the likelihood of being dis-abled (Taunyane and Hirschowitz, 1995).

2.2.5 Peri-urban issues

Descriptions of conditions in two slum areas in South Asia were found, which could well apply to slums globally.

In Baldia, a *basti* (slum area) in Karachi, overcrowding, constant water shortage and poor sanitation are problems (Murk, 1993). Van der Kroft (2002) describes a CBR project which enabled households to build their own latrine with soak-pits. But later on, when public sewers were in-stalled, households would reconnect their latrines to the main open drains, which created health hazards, and in addition, obstructed the freedom of movement of disabled people in the community. Alterna-tives to latrines, such as using bushes, are particularly difficult for dis-abled children and women in *bastis*. Water access is unreliable and inequitable, with the burden falling mainly on women, as housekeepers and often carers of people with disabilities.

Describing a slum area of Dhaka, Ahsan (2002) emphasises the unsanitary conditions of the toilets, unsanitary practices, and lack of knowledge about hygiene: 'most people use open places [as toilets] which pollutes the air and surroundings. Children with physical disabili-ties have to cross the dirty environment every day to use the toilets, which are not accessible.'

2.3 Psychological/attitudinal barriers

Sometimes the greatest barriers for disabled people are the negative attitudes and behaviour of family, of community, and of service providers, both in the government and voluntary sectors (Seeley, 2001). A 'complex of cultural, social and economic rules (UNESCAP, 1995a) can often be an even greater problem for the disabled person than the impairment itself (Gunnarson, 1998). Social barriers are often less easy to identify than physical barriers, and therefore less easy to change (Komardjaja, 2001).

2.3.1 Negative family attitudes

All over the world, prejudice against disabled people exists (Helander, 1999). Different cultures, religions and myths emphasise the disgrace of giving birth to a disabled child, who may be perceived as the result of anger of gods, or ancestors, the embodiment of sin in the family or of sin itself (Hurst, 1997).

Due to prevailing attitudes, superstition and ignorance, it is common for families to hide their disabled children, either because of feelings of shame, or to protect the child and themselves from negative social stigma (Ahsan, 2002). This is described in Nepal (Schofield-Gurung, 2000), in Yemen (Radda Barnen et al, 1998), and in Bangladesh (Zaman and Munir, 1990) among many accounts. Many disabled babies do not survive infancy (Krefting, 2001).

Disabled children are frequently over-protected by their families, resulting in limited interaction with their peers (Hanko, 1999; Pal et al, 2002). This may be from a misplaced sense of guilt on the part of families, (which, in the author's experience, is as common in the UK as elsewhere), combined with a lack of knowledge about the child's potential.

Unrealistic expectations are also common among parents with a disabled child. Many are highly fatalistic, or hope for a miracle cure. Others have 'too high expectations, pressurising their child to behave normally, and become frustrated when their child does not live up to their demands' (Zaman and Munir, 1990).

2.3.2 Community attitudes

In the African tradition, disability is reportedly viewed as a curse, a punishment from the ancestral spirits or God, for wrongs committed by one's parents. The family is usually isolated by the community, in the

same way that the family isolates their disabled family member (Longshaw, 1997). Negative stereotypes are common, resulting in low expectations of people with impairments, which can prevent them achieving their full potential (UN, 2002b). In Cambodia, disabled people are often excluded from society because they are thought incapable of contributing to family or community life (Hanko, 1998).

As a result, disabled children tend not to be sent to school, to play or mix with other children. 'In adulthood they become victims of ignorance, poverty, disease, discrimination and a whole range of negative attitudes - they become isolated from the general social systems' (Longshaw, 1997).

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). Cultural perceptions of water and purification rites also create problems for disabled people, and disabled women in particular (Van der Kroft, 2002).

Attitudes and behaviour can change with circumstances. In India, in an area with a problem of water fluorosis and a growing awareness of the cause of the disease, people disabled by skeletal fluorosis are no longer hidden. Instead they are commonly paraded by fellow villagers to officials and donors, in the expectation of attracting benefits to the village (Seeley, 2001a).

2.3.3 Conflicting accounts

Several researchers point out the dangers of accepting widely reported generalisations, which they do not deny exist, but they maintain are not the norm (Ingstad, 1999; Miles, 1995). Commentators do not always agree, so we should be wary of accepting one writer's account at face value. We need to know who the author is and on what experience they base their assertions. A male academic or journalist is likely to have a different perspective from a disabled woman.

A Western journalist writing in a UK newspaper asserts that physical disfigurement is taboo among the Masai, causing many of those injured to be 'hidden away' (Astill, 2002). This contrasts with an anthropologist's more in-depth account of the Masai, whose moral code dictates that 'impaired children should be treated exactly the same way as other children' (Talle, 1995).

Similarly, writing about disability in Zimbabwe, Mpofu's (2001) viewpoint contrasts sharply with that of Longshaw (1997) above. Mpofu asserts that having a disability does not necessarily lead to social rejection among rural Zimbabweans. Rural communities assume and expect full participation by people with disabilities in most aspects of community life to the best of their abilities, and are more accommodating of a broader range of human abilities. 'Illnesses and disabilities in individuals are presumed to be due to spiritual causation or disturbances in community life.' The disabled person 'is considered to be unwell for everyone else' and a 'kind of barometer of the quality of relations between the living and the departed ancestors, or God.' However, Chimedza and Peters (1999) present a more negative perspective of traditional treatment of a disabled Zimbabwean, including being abandoned on a mountainside to be 'cleansed'.

2.4 Institutional barriers

Negative stereotypes about disabled people result in discriminatory social policies (UN, 2002b), which in turn reinforce validate negative attitudes. Oliver (1998) claims that discrimination lies in the 'institutionalised practices of society' rather than in the attitudes of individuals. A prime example of institutionalised segregation and discrimination is that of the 'harmful, costly and intractable' residential institutions in countries of the Soviet Union (Tobis, 2000). However, most institutional barriers tend to be less obvious. They can include social institutions such as marriage, and hence the role of housewife and its attendant domestic tasks.

2.4.1 Lack of disability focused services

In low-income communities, the most common complaint is the lack of specialised facilities or systems of support, aids and equipment for disabled people and their families, as in Yemen (Radda Barnen et al, 1998). The reason may be financial constraints and low salaries, making jobs in health and rehabilitation unattractive (Hanko, 1999), and limiting the ability of authorities to implement services, or supply assistive devices (Philpott and McLaren, 1997; Siriwardane, 1997). Lack of training and expertise may be another factor, as in Vietnam, where therapists are scarce and inexperienced (Hanko, 1999). Trained therapists in India form part of the brain drain to the countries of the North (Payne 2002).

It is little surprise therefore, that no account has been found of support specifically related to access to water and sanitation facilities. In Bang-

ladesh, for example, this is because it is reportedly not considered an issue by organisations working with disabled people (CRP, 2002).

2.4.2 Ineffective services

Where services do exist, there is often criticism of the way they are implemented.

Centralised services: In South Africa, there is no clear policy for provision of assistive devices (ADs); long waiting periods and transport costs, particularly for those in rural areas, make it difficult to get access to a rehabilitation service, and to obtain ADs (McLaren et al, 1996; Philpott and McLaren, 1997).

Inappropriateness:
ADs are not always appropriate to the disabled person's living environment, e.g. the harsh conditions of a rural area, or cramped conditions of a peri-urban shack (McLaren et al, 1996).
Most equipment is imported into the country which is inappropriate for local use and conditions (Sachelo, 2002).
Top-down approaches and methods are introduced without regard to local culture, and with a lack of consultation with disabled consumers and their families (Kalyanpur, 1996).
Independence goals: professionals tend to take an overly narrow view of independence, e.g. as improved physical functioning, whereas the disabled person's view is often broader, and related to social and personal freedoms (Scherer, 2002). Van Brakel and Anderson (1998) noted a similarly narrow focus among professionals working in Nepal for people with leprosy. They acknowledge the 'quite widespread' use of certain ADs to hold spoons, pens and other tools, but point out that little attention is paid to assessing or alleviating the difficulties experienced by patients in carrying out ADL.

Lack of affordability: The cost of ADs is prohibitive for most. Taunyane and Hirschowitz (1995) found that more than half the African disabled respondents in the study did not have the appliances they needed, because of poverty.

Lack of consumer involvement in selection of ADs is apparently the single most important reason they are not used. Research shows that people will sometimes reject or abandon what seem to be well-designed and functional devices, for psychosocial reasons. Examples of reasons given are that the AD 'will make me feel more dehumanised' or 'will turn off' other people, or will appear 'freaky' or 'comical' (Vash, 1981, quoted in Day et al, 2002).

Negative attitudes of service personnel and bureaucracy are a problem (Bang, 1996; Philpott and McLaren, 1997). A study in Ireland shows that the way disabled people are treated when seeking information about a service can be a major cause of distress (Craddock and McCormack, 2002).

Lack of training, support and follow-up by AD service providers is reportedly the reason that one in three users in high-income countries abandon ADs (Craddock and McCormack, 2002). Community workers in low-income communities, potentially the most effective at village level, may be inadequately trained in socially sensitive areas of peoples' lives.

Servicing and maintenance: Much of this service is provided by hospitals, but again, long waits and costs of transport cause problems (McLaren et al, 1996).

2.4.3 Lack of information

In the current climate of increasingly accessible information technology in the North, it is easy to lose sight of the growing digital divide between North and South. More than half the people in Africa have never used a phone, let alone e-mail. A mere 0.3% of Internet hosts globally are located in Africa (DFID, 2000b). Internet access in Africa is monopolised by business (CRIN, 2000), making it more expensive for the average user than in the North.

At community level, families typically lack information and knowledge to meet the care and rehabilitation needs of their disabled members. In both Sri Lanka and South Africa, those in rural areas are additionally disadvantaged by a lack of information about services and options available (Bang, 1996), including free sources of help (Siriwardane, 1997). In Bangladesh, no printed information is available on access to water and sanitation facilities (CRP, 2002). Literacy rates in any case are very poor among disabled people and in rural communities, and written and print media have little effect on the majority of people (Balaram, 2001).

Individuals and families over the ages have improvised in their own situations, but the benefit of their ingenuity is often not passed on to others, because it is not documented or shared verbally. There are few social structures, civil societies or communication channels set up for this, especially in remote rural environments. Parent support groups in urban settings on the other hand, are able to do this (Payne 2002).

2.4.4 Lack of access to mainstream services/programmes

At an international level, although issues of disability are increasingly included in policies and strategies of many donor agencies, these do not yet appear to have made much impact on agendas of international NGOs, or on the political commitment of governments. Soewardjo (in Lysack, 1995) blames the impossibility of improving disabled people's independence on their lack of rights within the Indonesian Constitution.

A large study of more than 165 US-based relief and development NGOs found that disability is conspicuous by its absence (Singleton et al, 2001). 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.

In Bangladesh, there is an NGO Forum for Water and Sanitation, which comprises NGOs and GOs working with water and sanitation, but it does not include disabled people in their programme (CRP, 2002).

Lack of awareness and understanding is an important factor. Organisations and professionals lack knowledge about issues of accessibility (UNESCAP, 1995a). Design professionals for example, are largely unaware of the impact of barriers in the environment on older or disabled people and how these may be removed, often by simple planning at both strategic and detail level (Parker, 2001). In the Singleton study, it emerged that the 'attitudes and beliefs of organisation members were based not on accurate information but on commonly accepted assumptions and stereotypes' (Singleton et al, 2001). Lack of information about low-cost solutions perpetuates the perception that accessibility is costly.

At the same time, representatives of disabled people may lack expertise in defining and articulating the needs of their members, and may be unsure of the range of practicable technical solutions which they could request, and which could be provided at low, or no cost (Parker, 2001).

2.5 Poverty

The link between poverty and disability is now widely recognised. This is a global phenomenon, and applies to the UK (Oliver, 1998) as much as to low-income communities (Bonnet, 1997; Elwan, 1999; UNESCAP, 1995a). Poverty increases the likelihood of being disabled: in South Africa, poor living conditions and difficulties with ADL were found to be related (Taunyane and Hirschowitz, 1995). Poverty makes it more difficult

for families to minimise the impact of an impairment, and families lack the resources to access the care and rehabilitation, including ADs, that disabled family members need (May-Teerink, 1999; Taunyane and Hirschowitz, 1995; Radda Barnen et al, 1998).

2.6 HIV/AIDS

People with HIV/AIDS now widely recognised as disabled, both because of their resulting impairments, and the stigma and exclusion they experience. They are, for example, covered by the UK Disability Discrimination Act (DRC, 2002).

Very little information is available about disability and HIV/AIDS in low-income communities (Jones, 2001a). It is known that disabled people are at particular risk of contracting HIV/AIDS, because they lack access to health information, especially deaf people (Save the Children, 2000a). They are also at greater risk of sexual abuse, as they may be unable to protect themselves, or speak for themselves (NORAD, 2002).

Increasing numbers of older people (with or without disabilities) are drawn into caring roles for children whose parents have died of diseases such as HIV/AIDS. These children themselves are sometimes infected with HIV/AIDS, progressively incapacitated, and thus the caring role of younger generations for the elderly reverses (Helpage International (HAI), 2002a).

2.7 Impact of disability on families and communities

Unemployed or under-employed disabled people contribute little economically to the family. In addition, families incur costs caring for disabled family members (Metts, 2000), both because of health care expenses, and the reduced opportunities for income generation (Holdsworth, 2001). In this way their existence impoverishes the family (Tugwell, 1992, quoted in Jayasooria et al, 1997), pushing 'borderline households into poverty and poor households deeper into poverty' (Radda Barnen et al, 1998).

2.8 Disaster, conflict, post-conflict situations

Disasters and armed conflict are major causes of disability (Unnikrishnan, 2002). Millions of children are killed by armed conflict, but three times as many are seriously injured or permanently disabled (Healthlink, 1999; Machel, 1996), whether from amputations, head injuries, un-

treated stress or other trauma (Unnikrishnan, 2002). There is a lack of systematic information about disabled people in conflict situations (Ahlen, 1997), but plenty of anecdotal evidence suggesting that disabled people, especially children and the elderly, are often left behind when families are displaced by conflict or disaster (Ahlen, 1997; Jones, 2001a; Petty and Uppard, 1998). Many do not survive in such difficult circumstances (Petty and Uppard, 1998).

Disasters not only create disability, but destroy existing infrastructure and services that were meeting their needs. Unnikrishnan (2002) describes earthquake-hit areas in India: eight years after the 1993 Maharashtra earthquake, 'many paraplegics are still waiting for help, and in Gujarat, eight months after the earthquake, the future of amputees, paraplegics and others with special needs look uncertain'.
Conflict can leave a lasting legacy. In Cambodia, landmines were at one point causing 150-200 amputations a month (Bonnet, 1997). Twenty four years after the end of the war with the US, Vietnam had an estimated 4.4 million people disabled as a result of the war (Hanko, 1999).

Land-mine victim initiatives tend to receive a lot of media coverage, but much of the published literature (e.g. Harknett, 1999; Hastie, 1997) emphasises the error of implementing programmes focused only on war veterans, whilst neglecting those who were already disabled. Women and children are those on whom 'conflicts and landmines take a particularly high toll [because they] gather firewood, draw water and work in the fields' (Groce, 1997). Numbers of victims can be overestimated: in Mozambique it was discovered that many more people were injured and disabled by road accidents than by mines (Coleridge, 2002). In Cambodia, amputees are the major group of disabled adults, however there are nearly as many people with paralysis from polio (Semple, 1999). Many services in post-conflict situations focus solely on medical rehabilitation and the provision of 'hardware' such as prostheses (Harknett, 1999), with no attempt to learn from or build on existing community-based, holistic approaches to disability (Coleridge, 2002).

In Bangladesh, access to sanitation for people with physical impairments is extremely difficult in disaster situations. A report by the Centre for Services and Information on Disability (Ahsan, 2002) indicates that most emergency shelters have a single toilet for hundreds of people, which are unhygienic and inaccessible for physically disabled people. Wheelchair users cannot access the toilet in the chair, instead have to 'face a dirty environment', and as most disabled people do not use soap to wash their hands, because of a lack of help, their health is at risk. Families struggling for their survival are too busy to consider the needs

and health of disabled members. Even rescue workers do not have general knowledge on sanitation.

The news is not all bad, however. In some post-conflict countries, those disabled by the war are considered national heroes, as in Nicaragua (Bruun, 1995), and in Palestine (Giacaman, 2001), and led to the formation of a DPO in the Lebanon (Harknett, 1999). This view can persist long after the conflict. In certain parts of Viet Nam, there is a widespread perception that congenital impairments among babies are caused by the high levels of dioxin poisoning suffered by their parents during the war. Viewed as part of their 'heroic sacrifice', communities tend to be supportive to families with a disabled member (Jones, 1999b).

2.9 Issues related to particular groups

2.9.1 Disabled women and girls

Many women in low-income communities, especially rural areas, lead a life of subservience, with little control over their own lives (Coleridge, 1993). According to numerous accounts, disabled women face multiple discrimination for being female, disabled and poor (Abu-Habib, 1997; Groce, 1997; UNESCAP, 1997).

Surviving infancy is the first hurdle. In South Asia in particular, there are roughly twice as many disabled males as females (Helander, 1999), indicating that many disabled female babies do not survive infancy (Coleridge, 1993; ISCA, 1997; Radda Barnen et al, 1998). Those that survive are more likely to be abandoned (ISCA, 1997; Radda Barnen et al, 1998).

Disabled women are largely isolated and invisible (DAA, 1997; Seeley, 2001), and have least access to education. According to the UN Special Rapporteur, probably less than 5% of disabled women worldwide are literate (Lindquist, quoted in Singleton et al, 2001). Limited opportunities for skills training or income generating activities leave them in severe economic hardship and dependent on others (Singleton et al, 2001). They may be forced to beg (Coleridge, 1993). Disabled women are often confined to the home, whether for fear they may be exploited in some way (Thomas and Thomas, 2002), or in order not to obstruct the marriage prospects of other family members (Coleridge, 1993; Siriwardane, 1997). Even for women with minor impairments their marriage prospects are low. They suffer from social disrespect, neglect, malnutrition and abuse, disease and ignorance, are pitied and considered a burden. Mothers with disabilities face social stigma, poverty and

isolation (Groce, 1997; ISCA, 1997; Rahman, 2001; Seeley, 2001; Siri-wardane, 1997; Wahab, 1997).

Older people, especially older women, are frequently ostracised and even abused in communities for a variety of reasons and those with evident disabilities, physical and/or mental are particular targets of exclusion and mistreatment. Many disabled older people may lead highly unsatisfactory lives and die earlier than would be the case given adequate recognition and support (HAI, 2002c).

There are superstitions in some Indian village communities that the presence of disabled women is inauspicious in community gatherings (Thomas and Thomas, 2002). Some disabled women face difficulties in carrying out the household tasks expected of a woman in traditional societies, or may take longer, or require some assistance, which further reinforces the perception that they are ill-suited to running a household (*ibid.*).

In spite of their widely documented disadvantage, disabled women often find themselves marginalized both by development programmes targeting women, and by disability programmes (*ibid.*), where they are 'less likely to get rehabilitative care than men' (Groce, 1997). Disabled women and children together receive less than 20% of rehabilitation services (UNICEF, 1990, quoted in UNESCAP, 1997). A study of access to mobility aids in Uganda found that a third of the men had a wheelchair, but not a single woman (May-Teerink, 1999).

Singleton et al (2001) found that nearly half of US-based organisations that operate gender-specific programmes use no specific strategies to include disabled women, and 27 organisations providing training on gender issues do not specifically address issues of disabled women and girls.

Even where assistive devices may be available for women, the devices often do not suit them, because the views of disabled women and girls have not been sought. For example, wheelchairs are unsuitable for women who need to carry out household activities at ground level (UNESCAP, 1997).

2.9.2 Disabled children

Disabled children are doubly marginalized, both by programmes and services targeted at children, and by rehabilitation programmes. Disabled children and women together receive less than 20% of rehabilitation services (UNICEF, 1990, quoted in UNESCAP, 1997). At the same

time, it was difficult until recently to find any references to disabled children in general information about children. NGO literature on child rights for example, rarely mentions disabled children (Jones, 2001a).

Traditional children's tasks, such as carrying water, can cause increased impairment in a disabled child, where the heavy weight creates problems of bone deformity. However, such activities also contribute to the social rehabilitation of disabled children. The dilemma is that 'a disabled child who cannot fully participate in household work may be deprived of an important part of their socialisation experience.' (Boyce et al, 2000).

2.9.3 Disabled elderly

Parallels have been drawn between the situation of elderly and disabled people (many are both), in particular the threat of poverty, neglect and their marginalization in the development process (ACP-EU, 2001; UN, 2002b). Data compiled by HAI (2002c) clearly shows that the incidence of impairment and disability increases with age. The proportion of the older population (65 and over) with a disability may be as much as twice that of the total population, and has been estimated to reach 80% in people over 85. The onset of disability in old age has a great impact on older people's quality of life and levels of poverty.

In many low-income communities, such as Tanzania, elderly people are traditionally cared for by their family (Macha, 2002). Elderly people are increasingly being forced to cope alone, however, for a variety of reasons, including a steady rise in numbers of elderly (Nugegoda and Balasuriya, 1995), economic hardship, and the breakdown of tradition families ties and values (Aboderin, 2002). In parts of sub-Saharan Africa, and even China and Vietnam, elderly people increasingly find themselves the main care-givers in families hit by HIV/AIDS (HAI, 2002a).

Age brings with it increased likelihood of physical limitations in functioning, the commonest being bathing and feeding, getting in and out of bed, and using the toilet (Nugegoda and Balasuriya, 1995; Taunyane and Hirschowitz, 1995). This can result in a loss of dignity (UNICEF, 2000). The risk of impairment-causing accidents among elderly people using toilets is documented, e.g. falling off commodes (Nazarko, 1995), or slipping when using an Asian style squat toilet (Travers et al, 2001).

Dementia, which increases in prevalence with age, can be equally disabling, as it reduces the ability of elderly people to care for themselves (ADI, 1999a).

2.9.4 Race / caste

A few references were found related to the multiple disadvantage of disability, race and poverty. Elderly coloured or black people in South Africa tend to develop functional limitations earlier than whites who live in better socio-economic conditions (Taunyane and Hirschowitz, 1995). Elderly Africans are identified as the most disempowered group.

In India, caste issues can aggravate access to water, for example, by dictating who is allowed to use the same well (Carrington, 2002; Seeley, 2001b).

2.9.5 Hierarchies of impairment

Some impairments tend to be more stigmatised than others (DAA, 1999, Jones, 2001a). Reasons for this may be lack of understanding of the cause, superstition, or negative perceptions of how the person looks, sounds or behaves. A child with a physical impairment resulting from polio, for example may be accepted and included by the community, whilst epilepsy is still considered contagious in many countries. In Ghana 'particularly negative attitudes were reported towards children with a learning disability or epilepsy, although those with visual impairments and physical disability are viewed more positively (DAA, 1999). Such stigma can lead to isolation, abuse and neglect.

2.10 Summary of issues

There is an international body of literature on the issues and barriers facing disabled people, but which tends to be dominated by writers from the North. There is a significant lack of information about disabled people in low-income communities generally, or about disabled women, and very little about their access to water and sanitation.

The most frequently documented areas of concern in low-income communities are those of general mobility and ADL, where the most apparent barriers are to do with the individual limitations of disabled people themselves, and the inaccessibility of the physical environment. As mobility and use of water and sanitation are integral to ADL, and mobility or lack of it are inherent in both, these barriers are clearly equally significant to water and sanitation.

It is important not to overlook the significance of attitudes, knowledge and behaviour of communities and organisations towards disabled people. Although not much has been written about this area, local cultural

beliefs related to water and health can contribute to the marginalization of disabled people. Any initiatives to improve access to water and sanitation must address not only the individual limitations and physical barriers, but equally the social barriers to participation, which can be just as much a problem for disabled people.

It important to understand local definitions and perceptions of disability, both positive and negative, in any efforts to improve perceptions. There is some significant work being undertaken in this area which the project needs to be aware of, in order not to duplicate efforts, and in order to understand how work related to water and sanitation can link in with it.

Many of the barriers and difficulties are faced by all disabled people, whatever their impairment. Disabled people are a heterogeneous group, who face different problems and barriers depending on age, gender, and type of impairment. It would be unrealistic for the project to aim to address all the specific issues arising from every type of impairment. It will therefore be necessary to be clear about what will and will not be addressed.

The local culture and circumstances will also determine the kind of social and environmental barriers that arise. This wide range of cultural perceptions means that it will be a challenge to produce outputs which have global relevance.

3. Service provision for disabled people

Improving access for disabled people to water and sanitation requires the removal of the numerous barriers to their participation that have been described. This chapter provides an overview of the literature that discusses *how* this may be done. Firstly the legislative context related to disability is briefly examined, then some of the key issues in service provision discussed, illustrated by examples from both high-, middle- and low-income countries.

3.1 Legislative Context

Although this research is focused at community-level, it is important to mention the crucial role of legislation and policy in establishing a framework of rights for disabled people, as it can either underpin or undermine activities at community level.

Legislation has been summarised as falling into four main categories: welfare-based, service-orientated, enablement and rights-based legislation (UNESCAP, 1995b). These categories reflect society's gradual shift over the last 20 years from a perception of disabled people as 'objects of charity', to recognition of the need to enable them to participate in society, to the introduction of measures to protect their entitlements on an equal basis. In other words, 'a shift from charity, to enablement, to entitlement.' (*ibid.*)

The UN Standard Rules (UN, 1993) have provided a framework for many countries to introduce rights-based legislation. But there often remains a gap between policy and practice. Detailed policies are needed, outlining roles and responsibilities, and allocating resources to support implementation, if the words on paper are to be translated into practical changes.

3.2 Key issues for low-income communities

Social services in low-income communities vary between countries, but the general picture is of an absence of comprehensive social safety nets, and inadequate and inequitable health care provision. Disabled people tend to rely heavily on informal home-based care, as any rehabilitation services that do exist tend to be based in urban areas, and so financially and geographically inaccessible. Because of this relative scarcity, less literature is available about services for disabled people in

the South than in the North, and references to access to water and sanitation even rarer.

Nevertheless, enough information was found to be able to draw together some of the key factors that impact on effective service implementation.

3.2.1 Location: Centre-based or Community-based

In Western Europe, institutional care has largely been rejected in favour of community-based care, i.e. in people's own homes or in supported accommodation, with support primarily family- and community-based (Baldock, 1998). In the South, the main focus of debate around disability services is on issues of community- versus centre-based provision.

Institution-based rehabilitation (IBR) and care

The institutional model of care was imported from North to South: most institutions in middle- and low-income countries were founded either by Western missionaries (Ojile, 2000), or by charitable organisations or individuals, rather than governments (Chimedza and Peters, 1999). Institutions can vary in size from large hospitals to small community-level centres, providing treatment and care on an out-patient, short-term residential, or long-term residential basis. In former Soviet-bloc countries in particular, a comprehensive network of residential institutions was the mainstay of disability provision, providing a function of segregation, training and education (Tobis, 2000).

Advantages of institutions include:
- A limited number of qualified staff can treat a high volume of patients.
- Limited expensive equipment can serve a large number of people.
- If residential, disabled people avoid having to travel long distances.
- Specialised treatment and care can be provided that would be technically impossible or onerous for families, e.g. for spinal cord injured people (Hans, 1999).
- After hospital treatment, patients may need a period of transition to learn new skills, and ways of managing their impairment or condition (Hans, 1999; CRP, 2002), often alongside family members, thus maximising their use of time and avoiding repeated travel.
- Training: many institutions double as a training facility: the Centre in Battambang, Cambodia, the only rehabilitation provision for people with quadriplegia and paraplegia, has a capacity of only 36 patients, but also provides training for health workers at provincial hospitals (Bonnet, 1997).

Disadvantages of institutions include:
- Low coverage: centres cater for as few as two per cent of disabled people in low-income communities (Siriwardane, 1997).
- High cost (Tobis, 2000; Chaudhury et al, 1995).
- Distance: disabled people often are not mobile, or long journeys exhaust them (Chaudhury et al, 1995; Semple, 1999).
- Difficult to take time off work, or to leave the family for extended periods of time (Craddock and McCormack, 2002; Semple, 1999).
- Increased risk of abuse of children, especially in residential settings (Chaudhury et al, 1995; Cross, 1998; Jones, 2001a).
- Out of context: isolation from home/school/work setting, increases the risk of inappropriate solutions and difficulties with re-integration (Chaudhury et al, 1995; Craddock and McCormack, 2002; Hollingsworth, 2001).
- Reinforcing stereotypes – that disabled people are dependent and suitable to be segregated (Moyes, 1981).

Outreach

In recognition of some of these drawbacks, many institutions have responded by developing outreach services in various forms:
- Home-visiting and follow-up by centre professionals, eg Orissa (Hans, 1999). This model is also followed by the Urban Community Dementia Services (UCDS) in Kerala, India, providing home visits, day care, training, and support for carer self-help groups (Shaji and Roy, 1999).
- Distance support: the Bangladesh Protibondi Foundation developed 'distance training' for families from remote rural areas. Families with a disabled child attend a centre for 2-5 days, to receive advice – assessment, teaching suggestions and instructions – which they then carry out at home. They return for further advice after 1-3 months, or receive support through correspondence (Zaman and Munir, 1990).

Care in the community – the 'informal sector'

The term 'informal sector' is often used to describe the unpaid provision of services to people with dependencies living in the community, usually by family, friends and neighbours. Ungerson (1998) calls it the linch-pin of the UK's community care system, where public social services provide only a fraction of social care, with the majority of disabled people relying for help with personal and domestic tasks on 'informal carers' – usually female family members (Baldock, 1998). Oliver and Barnes (1998) maintain that this is 'often to the economic and emotional disadvantage of both disabled people and their families', whilst Dalley (1998)

concludes that community care is geared to the needs of the health or social care practitioner rather than the disabled person.

In the South, where the option of state provision is largely non-existent, it is traditionally seen as the responsibility of families to care for disabled members. This is reportedly the case in Malaysia (Jayasooria et al, 1997), Sri Lanka (Nugegoda and Balasuriya, 1995; Siriwardane, 1997), and Cambodia (Mony, 2002).

Indigenous forms of care

A commonly held assumption is that traditional attitudes and beliefs about disabled people in low-income countries are all negative, and that until the arrival of Western ideas, disabled people were entirely neglected. This is untrue; throughout the world, there is a continuum of attitudes and beliefs towards disabled people (Kisanji, 1995a, 1995b). So-called new concepts such as community integration are not new in many low-income communities (Kisanji, 1995b; Miles and Hossain, 1999; Mpofu, 2001).

In rural areas of Zimbabwe, for example, rehabilitation services are apparently informally provided by families, communities, traditional and spiritual healers, focusing on personal development and functional skills for community living. The treatment would include the individual, extended family and community, i.e. a holistic or community-oriented perspective (Mpofu, 2001).

Community-based rehabilitation (CBR)

CBR was originally designed by WHO to bring rehabilitation services to the 95% of disabled people in low-income communities for whom IBR is inaccessible (Helander et al, 1989; Helander, 1999). It is now recognised as a multi-sectoral approach, and has the endorsement of ILO, UNICEF and UNESCO:
> 'CBR is a strategy within general community development for rehabilitation, equalization of opportunities and social inclusion of all children and adults with disabilities.
> 'CBR is implemented through the combined efforts of people with disabilities themselves, their families and communities, and the appropriate health, education, vocational and social services.' (ILO et al, 2001)

The original WHO medical service delivery model of CBR is implemented in some countries in a 'top-down' way through the Ministry of Health, as in Vietnam and China (Jones, 1998; Purves, 2000; Tran and Nguyen, 1995). Implementation can also be through local district health

structures, as in Lesotho (Mohale and Miles, 1995) or Myanmar (Jones and WV/UK, 1999).

Over the past two decades, the recognition that disability is not only a health issue began to be reflected in the variety of government sectors implementing CBR. In Guyana, CBR is implemented through the Ministry of Education (O'Toole, 1990, 1995), whilst in Yemen, the Ministry of Insurance and Social Affairs takes the lead (Radda Barnen et al, 1998).

Elsewhere, local or international NGOs may be the main implementer, e.g. Handicap International in several countries, including Cambodia (Semple, 1999), and numerous local NGOs in India, most with INGO support (e.g. Lang, 1999; Asia Pacific Disability Rehabilitation Journal; Disability Dialogue).

The concept of CBR has also evolved significantly over the last two decades, with increasing emphasis on human rights and community participation (ILO et al, 2001). CBR programmes supported by Save the Children/UK for example, have seen the following changes:
▪ from 'service delivery' towards empowerment/rights-based approaches.
▪ from working within institutions, towards alternative community-based approaches.
▪ a holistic approach to disabled people's development (not just focusing on physical rehabilitation).
▪ from approaches which see disabled people as target beneficiaries, towards working with, and promoting the participation of, disabled children and adults (Stubbs, 2000).

Other CBR programmes have seen their role as helping disabled people gain access to existing mainstream services (CRP, 2002; Jones, 1998; Krefting, 2001).

Strengths:
• **Increased provision:** CBR has benefited disabled people in rural areas with previously no services (Radda Barnen et al, 1998).
• **Support for ADL**: CBR is good at providing practical advice to enable people to wash and feed themselves, to wash clothes, fetch water, and at providing moral support and a sympathetic ear (Dolan et al, 1995).
• **Holistic:** takes account of all aspects of the disabled person's life in the home and community.
• **Community involvement:** active participation of local communities increases the likelihood of inclusion of disabled people in community life (Mpofu, 2001).

- **Benefits to the wider community**: CBR can act as a catalyst for social mobilisation (Giacaman, 2001), or provide new or improved services, e.g. water and sanitation, improved roads, an accessible playground, that benefit the whole community (Lysack, 1995; Miles, 1995).

Concerns:
- **The role of women**
An important issue is the often unacknowledged, unpaid role of women in community-based care. In the UK, community care inevitably means reliance on care by the family, in particular the mother, which is often taken for granted (Ayer and Alaszewski, 1984; Twigg, 1989). Dalley (1998) found little evidence that anyone other than family members get involved in informal care, likewise Parker (1993) found that friends and neighbours are only a small minority of regular carers. Cochrane and Clarke (2000) stress the importance of recognising this reliance on female carers when making judgements about the benefits of different approaches to care.

As women age, their capacity to continue their role as carers may diminish, as they themselves succumb to the sometimes disabling effects of ageing (HAI, 2002c).

These criticisms have also been raised in the South. Giacaman (2001), whilst acknowledging that CBR has, in some instances, helped decrease women's burden of care, nevertheless criticises the demands it makes on the 'already burdened lives of women' in Palestine. CBR takes advantage of 'pre-defined care-taking roles dictated by a patriarchal society', which exclude women from seeking paid work, in favour of a voluntary care role.

The challenge for communities in both North and South will be to identify future informal carers, as extended families break down, and as more women enter paid work (Jayasooria et al, 1997; Komardjaja, 2001), and to identify the most appropriate forms of support for carers (Ungerson, 1998).

- **Top-down implementation:**
In some projects, only the location of the service has changed; decisions are still made by the same rehabilitation professionals, based on traditional medical views of disability (Lysack and Kaufert, 1996).

- **State v community responsibility:**
There is a misconception that community-based means that all CBR activities should take place at community level. This is not the

case, in fact it is essential that governments be involved, to provide the network of referral and technical support needed by CBR (Helander, 1999). Where health and rehabilitation services are poor, the perceived need may be to strengthen state provision, not risk weakening it by challenging it (Giacaman, 2001; Lysack, 1995; Lysack and Kaufert, 1996). Giacaman argues that promoting community-based approaches may relegate disability provision to an optional charitable activity, thus absolving the state of its responsibility.

- **Reliance on volunteers:**
  Volunteers are well suited to short-term 'mobilisation' or 'campaign' style activities (Jones, 1998), but may be inadequate in long-term service provision (Giacaman, 2001), particularly in communities where volunteering is not part of the culture, such as Zanzibar (Jones and UWZ, 2001).

- **Lack of local 'ownership':**
  Over-dependence on outside experts, and lack of attention to incorporating local socio-cultural support systems, knowledge and practices, can jeopardise long-term viability, and result in programmes that collapse as soon as experts leave (Mpofu, 2001).

- **The urban challenge:**
  CBR was conceived with rural areas in mind, but with increasing urbanisation in many countries, there is a need to turn attention to urban slum areas, where access to services is poor and often expensive. Thomas and Thomas (2001) warn that the likelihood of community participation here is far less, as populations lack cohesion, are often floating or transitory in nature (Murk, 1993), with little formal structures or leadership. Families with both spouses working have little spare time to take on the rehabilitation of their disabled members.

Combination of approaches

Some programmes use a combination of the above approaches, in both South and North, (although the term CBR is not widely used in the North). The CRP in Bangladesh is one example, where treatment is first provided at a Centre. Patients are then prepared for return to the community at a transit hostel, where occupational therapists and social workers inform patients about adaptations to housing and facilities for ADL. A CBR programme then provides follow-up and home visits in the community (CRP, 2002). A weakness is that, on their return to the community, most disabled people do not make appropriate changes to

the home, or to facilities for accessing water and sanitation (Hollingsworth, 2001).

3.2.2 Control and decision-making: the role of disabled people

The importance of involving disabled people and their organisations in developing legislation, policy and services is widely recognised (Hurst, 1999; Lang, 1999; MIUSA, 2002; NORAD, 2002). As the 'experts on disability' (Williams, 1995), disabled people have a 'key role' in the formulation and implementation of disability strategies (UNESCAP, 1997) and CBR programmes (ILO et al, 2001). Action on Disability and Development, a UK-based INGO, argues that governments need to learn to work with, not just on behalf of, disabled people, if they are to achieve their poverty reduction goals (Yeo, 2002).

The ideal is genuine partnership with DPOs, i.e. organisations *of*, rather than *for*, disabled people, going beyond mere consultation about needs and implementation, and extending to programme planning and decision-making. This should include identifying the kinds of service to best meet those needs, how services are provided and by whom, and organisational establishment (Lysack and Kaufert, 1996; Johnson, 1998).

However, it is widely acknowledged that this is a challenge. Andrich and Besio (2002) emphasise that in order to ensure that terms like 'decision-making' or 'partnership with professionals' are more than empty rhetoric, disabled users must be given 'the educational possibility to become informed, demanding and responsible'.

> 'It is important to show how people with disabilities and carers can participate in the design, construction and control of water systems at the household and community level. If people with disabilities, carers, families and communities can be assisted to understand the needs of all people and to find local solutions that will be helpful. Similarly if they can learn as community members how to negotiate with the relevant authorities to achieve access for all, and to make them aware of local low-cost alternatives, that will be helpful to make structural changes.' (Van der Kroft, 2002)

Strategies are needed to enable disabled people to carry out self-advocacy, particularly in capacity-building for self-help groups (Seeley, 2001). In Ethiopia, Save the Children (2002a) takes a twin-track approach: on the one hand working directly to support disabled children, and on the other, supporting an Ethiopian Federation of Associations for disabled people. Mobility International USA has produced a list of activities to help organisations promote the inclusion of disabled women in

the development process (MIUSA, 2002). The reality is, however, that little attention is paid to the development of capacity of DPOs (Johnson, 1998; Lysack and Kaufert, 1996; Seeley, 2001).

A cautionary note is raised however: DPOs do not automatically represent all disabled people. In both high and low-income countries, DPOs tend to be dominated by men with physical impairments, from certain social classes and ethnic groups (DeJong, 1979, quoted in Lysack and Kaufert, 1996; Harknett, 1999; Yeo, 2002). They often have weak links with rural communities (Ingstad, 1999), disabled women and children, or more marginalized groups such as the deaf or those with learning or mental health difficulties. Some have a welfare-based rather than rights/ development-based approach (Save the Children, 2000a). Many disabled 'leaders' who are internationally recognised, often have only a limited profile in their own countries (Lysack and Kaufert, 1996).

3.2.3 Disabled people gaining control: Independent/Integrated Living

The Independent Living (IL) movement began in the US in the 1960s, as a disabled consumer-initiated challenge to the control of the medical profession over their lives. A key feature was self-advocacy for disabled people's rights and needs, in the context of a well-developed system of rehabilitation, and an established social safety net. It identified environmental and attitudinal barriers to access and equality (Lysack and Kaufert, 1996). Its impact in practical terms has been to achieve dramatic changes through the elimination of environmental barriers, modification of discriminatory practices, and introduction of disability rights legislation. Centres for Independent Living (CILs) have developed throughout North America and the UK, (in the UK they are often called Centres for *Integrated* Living) offering peer counselling, consumer-based research, advocacy and self-help.

Independent/integrated Living – relevance to low-income communities

Debates about the appropriateness of Northern concepts and approaches to countries of the South are particularly relevant when it comes to IL. Lysack and Kaufert (1996) point out that 'cultural values emphasising self-determination, independence and empowerment … may be irrelevant and even frightening concepts in many international contexts.' Even recognising that IL means more than simply living on one's own, but rather 'having the rights and the opportunity to pursue a course of action' (Lysack, 1995), this is still an unrealistic and inappropriate goal in many cultures.

Commentators from the South concur. Komardjaja (2001) questions the appropriateness of a goal such as independent mobility in collectivist Asian cultures such as Indonesia, where human assistance is the norm, and culturally more acceptable than using assistive devices. From India, Ghosh (in Lysack, 1995) comments that 'inter-dependent living' describes more accurately how all people live, whether disabled or not.

Inter-dependence is illustrated by the account in Boyce et al (2001) of six disabled young women living together in order to attend a vocational training programme. They co-operate on tasks that they would not be allowed to do if living at home with their families, or would not be capable of if living alone. One woman describes the collaboration involved in fetching water, with each contributing according to her strengths: "'There is a tap next to our room. Mohua will lift the water, give it to Namita, and she gives it to me and I carry it.'"

Mulholland et al (1998) suggest that, in the provision of assistive technology, independence may be a less important consideration than quality of life. Examples of relevant aims could include reducing unhappiness, preventing clothes getting dirty, and the ability to carry out one's role in the family.

3.2.4 Disabled people gaining control: Direct payments

The 1997 UK Direct Payments Act gives local authorities the power to implement schemes whereby payment is made directly to the disabled user, to support independent living, instead of a service being arranged for them. Direct payments allow disabled people to take control of the decisions which affect their lives, and to make their own arrangements for services they need.

Benefits include widespread support among disabled consumers (Zarb et al, 2000), and their apparent cost-effectiveness (Dawson, 2000). Issues remain, however, to do with complexity of implementation, the need for local authorities to change from a culture of direct service provision, and a new relationship with users (*ibid*.). For consumers, information, advice and support are needed, so that they feel confident to use direct payments (R-Dis, 2002). Furthermore, services have been found to vary considerably in terms of quality, responsiveness and value for money, especially in rural areas (Read, 1991).

Where disabled people are involved in direct service provision, e.g. in an outreach programme in rural Ireland, they have been able to 'build a relationship of trust and credibility' with consumers. Disabled people

were trained to provide a support and liaison role between service and consumer, to form local support networks, and to act as both role models and provide 'peer support' (Craddock and McCormack, 2002).

3.2.5 Initiatives led by Disabled People's Organisations in the South

Whilst DPOs in the North tend to focus primarily on advocacy, in the South, the social policy, professional skills and services which are taken for granted in high-income countries are largely absent. The focus of DPOs in the South, understandably therefore, tends to focus more on self-help projects. Numerous examples are documented; a few are described here to illustrate the range of activities.

In some cases DPO projects are operated independently of government. The National DPO of the Philippines, KAMPI, runs Stimulation and Therapeutic Activity Centres (STACs) to provide appropriate assistive devices, and training for independence for disabled children (Ilagan, 1998). The Bangladeshi DPO Protibandhi Kallyan Samity implements a wide range of activities, including education support, medical support, awareness campaigns, job placement, self-esteem building, and home-based therapy for disabled people (Carew, 2002). The programme concept and vision come from the DPO, but may be implemented in collaboration with non-disabled staff (Ilagan, 1998).

Elsewhere, DPOs collaborate with government in implementing CBR programmes. The Zanzibar Association of Disabled People collaborates with the Ministry of Social Welfare (Coleridge, 1993; Jones and UWZ, 2001). 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, 2001a). The link between practical implementation and influencing government is made – DPOs need to initiate programmes that will inform governments and local authorities on the importance of providing accessible facilities (Sachelo, 2002). According to the President of a local DPO in Thailand, the most effective way to encourage major changes in society is to support 'leaders of physically disabled people in the community …to represent people with disabilities in advocating for their rights, including the right to access to water and sanitation' (Kulkhanchit, 2002). The Director of a National DPO in Zambia goes further, suggesting that DPOs should 'sit down with town planners and architects to come up with ways of making most facilities disabled friendly'. DPOs should 'seek representation in most commu-

nity development committees so that persons with disabilities can make decisions that are in line with disability needs' (Sachelo, 2002).

A small number of examples were found of disabled people becoming active in general community development initiatives. Two examples were identified of disabled women getting involved in the development of village water provision – in Bihar, India (Ghosh and Martinez, 1998; Lysack, 1995) and in Bangladesh (Van der Kroft, 2002). In Zimbabwe, a group of disabled women spent several years raising the funds to build their own well, because other women charged them high sums to ride on donkeys to fetch water (Hurst, 2002). In Zambia, at a government-run community centre for disabled people, the inhabitants put pressure on the government officials to install piped water, because it was previously too far to walk to fetch water (Sachelo, 2002).

3.2.6 Partnership in technology design

Empowering a disabled person is not just a case of providing a wheel-chair, for example (Bang, 1996). The literature on ADs advocates a client-centred approach, with 'the user as the starting point, never the technology' (Scherer, 2002), and with the intended consumers as participants in the design process (Mulholland et al, 2000; Scherer, 2002; Werner, 1998). Professionals should make available a choice of options to consumers, as meaningful involvement in the decision-making will result in more consumer satisfaction (Scherer, 2002), and improved effectiveness and outcomes (Mulholland et al, 2000).

Mulholland et al (1998) caution that AT should not be considered solely from the perspective of the user, but also take into account the goals and values of caregivers, so as to determine the impact of the device on all involved, including carers' ability to fulfil their responsibilities (Nazarko, 1995). A mock-up (rough prototype or model) should be introduced to potential users as early as possible in the design process, to solicit feedback and advice on design (Mulholland et al, 2000).

3.2.7 Control and decision-making: the role of the family

In the North, a major role has been played over the years by organisations of parents of disabled children, in challenging government policies, in initiating innovative services, and in promoting the rights of their disabled children. UK examples are Mencap, the organisation of parents of children with learning difficulties (Mencap, 2002), and the Alliance for Inclusive Education (Allfie, 2002).

A number of examples were also found of parents in the South, particularly mothers, of disabled children taking a lead in developing their own services. In Manila, Philippines, a group of mothers run their own CBR programme (McGlade and Aquino, 1995). In Tbilisi, Georgia, a telephone help-line has been set up by a parents' organisation, to provide information and support for other parents (Jones, 2000).

The Lesotho Society for Mentally Handicapped People not only provide support to other parents, but are also involved in providing training and support to teachers with disabled children in their class (Mphohle, 2000). In South Africa, the parents' organisation DICAG campaigns to raise awareness of disability and for equal opportunities for disabled children, especially in education (DICAG, 2002).[1]

International NGOs can provide the impetus to set up such parents' groups, where families and children with disabilities can give and receive support and assistance (Gunnarson, 1998; Save the Children, 2002a). Some of the most powerful impetus can come from Parents' Associations in the North, in fostering emerging groups in the South (Skogmo, 1995). Grandparents are also an increasing resource for this, but often need support when their own capacities are limited (HAI, 2002a).

3.2.8 Cultural differences in child development

Examples were found of different culture-bound views of what young children in general need to learn, and the skills they should develop, which are equally relevant to disabled children's development.

Emblen (1995) found major differences between teachers of young children in England and in Laos, and what they value for children to learn. In England, teachers stressed autonomy, self-expression, and independence, whilst Lao teachers stressed social values: politeness, caring and respect for others.

Kambalametore et al (2000) found that in a rural village in Malawi, a well-adapted child aged 4-5 is expected to show social responsibility, through respect, obedience, co-operation, the ability to socialise with other children, to carry out 'children's chores', and to have sufficient memory to carry messages. Examples of skills anticipated around this age are washing up, carrying water on the head, and bathing without help. Such a child is described as intelligent or clever. Western con-

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[1] Further examples of parents' organisations can be found on the EENET 'Parents' webpage: http://www.eenet.org.uk/parents/parents.shtml

cepts of intelligence on the other hand, concentrate on the dimensions of reasoning, communication and physical coordination. Participation in domestic water chores and independence in personal hygiene and sanitation, therefore, are determined by cultural values.

3.2.9 Resource allocation

The effectiveness of a service depends less on the level of available resources, and more on how they are distributed (Stubbs, 1996). Decisions about how to allocate a finite quantity of resources face service providers globally; social policy is partly about how these resources are rationed, and their sources (Lister, 1998). The welfare provision model of high-income countries is often seen as an ideal to which low-income countries aspire; for this reason it is worth a brief examination.

Welfare provision - targeting

Cochrane and Clarke (2000) broadly categorise implementation of welfare provision as:
Rights-based, founded on the principle of *social* citizenship; that every member of society has a right to participate fully in society.
Residual welfare: means-testing targets limited resources at the poor who cannot afford private insurance.
Discretionary approach, based on an assessment of an applicant's needs by professionals.

The discretionary approach dominant in the UK is based on an assessment of individual needs by a team of professionals, who assess the physical, psychological and social functioning of the disabled person and identify areas of limitation. A package is devised to remedy the limitations, in consultation with the individual and family. In addition, state financial support is available as an array of benefits, including incapacity benefit for those unable to work, mobility allowance, and attendance allowance, which contributes towards personal care (Hollingsworth, 2001).

Welfare provision - sourcing

Services provided may be either state-funded, insurance-based, or what is often referred to as a 'mixed economy of welfare' (Johnson, 1998). Most welfare states are currently trying to reduce their role in provision, to take more of a planner/funder/ manager role, and to rely increasingly on commercial, voluntary and informal sectors (*ibid.*).

Benefits of the welfare system for disabled people are that the majority now have access to relatively more services, and are less likely to live away from families in an institution than they would have fifty years ago (Oliver and Barnes, 1993).

Criticisms of welfare provision tend to focus not only on resource levels, but also on issues of access, equity and control:
- the dominance and invasion of privacy by professionals and bureaucrats, who control and dictate the services provided.
- inadequate support for families.
- lack of consultation with users or responsiveness to their expressed needs.
- reinforces rather than alleviates dependence and discrimination.
- care plans may not be implemented because of lack of resources.
(Bagilhole, 1997; Baldock, 1998; Jackson, 1998; Oliver and Barnes, 1993).

These concerns are also mirrored in a review of the Assistive Devices service in KwaZulu-Natal, South Africa, which made the following recommendations:
- Provision of mechanisms to make ADs "affordable for all".
- Improved information systems regarding disability.
- Promotion of community-based service providers' role as 'enablers'.
- Promotion of environmental accessibility.

(Philpott and McLaren, 1997)

This issue of control is a key feature of direct payments (see Section 3.2.3). An argument in favour of direct payments maintains that 'value' and 'cost' are not necessarily the same. Hills (1998) points out that a disabled person may value more highly the freedom to spend a smaller cash sum how s/he likes, than to receive a particular service that costs more to provide.

3.2.10 Mainstreaming and community development

Mainstream development organisations are increasingly recognising that disability is a development issue, and a few examples have been found that describe their work alongside disabled people (Hossain, 1997). At a local NGO level, the NGO Young India Project organises members of the 'land-deficit' classes to fight for land, higher income and a more egalitarian society. It identifies disability as one form of oppression of its members, and has helped set up self-help groups of disabled people, to support each other and campaign for their rights (Mediratta and Smith, 2001; Seeley 2001a).

Strategies of INGOs such as Save the Children/UK and Sweden explicitly include disability as a cross-cutting issue to be implemented across all programmes. In East Asia, disabled children have been explicitly included in work such as support to welfare homes in China, women's savings and credit programmes in Vietnam, kindergarten and primary education programmes in Laos (Jones, 1999b), and in the education programme in Tajikistan (Jones, 2001b).

SAFOD, an umbrella DPO in Zimbabwe, is working together with an HIV/AIDS communication organisation to address issues of HIV/AIDS among disabled people in Southern Africa and (Payne 2002).

In post-conflict and disaster situations, there are examples of agencies that include disability as an integral part of their response programme. In Afghanistan, a UNDP joint integrated development strategy oversees collaboration between community mobilisation structures (Habitat in the towns and the Afghan Rural Rehabilitation Programme in the rural areas), and technical programmes such as the Food and Agriculture Organisation and the Comprehensive Disabled Afghans Programme (Coleridge, 2002). In Angola and Macedonia, Oxfam has been building latrines in settlements for displaced people, some of which are designed to be accessible to people who have lost limbs through landmines (Bastable, 2002).

The destruction of old systems through conflict or disaster can also be seen as an opportunity for change. The conflict in Bosnia brought an influx of international agencies, and opportunities to learn about the successes and failures of approaches from other countries. This resulted in the development of new community-based initiatives for disabled children (Hastie, 1997). The main author was working in China when Save the Children was asked to support the reconstruction of several residential welfare homes that had been devastated by floods in 1997. The opportunity was used to introduce training in more appropriate approaches to child-care, including care of disabled children.

A range of materials has been produced to support an inclusive approach, notably a Manual on Inclusive Planning published by the UN and STAKES, Finland, with a Rapid Handicap Analysis (Wiman, 2001). Focusing on emergency situations, a UNHCR training manual, Action on the Rights of Children, has one Critical Issues Section about how disabled children can be included (UNHCR and SC Alliance, 2000). Save the Children's series 'Working with Separated Children' includes an information sheet on the relevant issues for disabled children (Petty and Uppard, 1998). No information was found, however, about how or whether these materials have been used to make a difference.

3.3 Researching disability: issues

Disability research has traditionally been done by non-disabled, often medical researchers on disabled people. Disabled researchers have become active in recent years, and have voiced strong opinions about earlier research, which has been described as often insensitive, unethical, and contributed to the oppression of disabled people (Barnes, 1997; Barnes and Mercer, 1997; Oliver, 1997). The idea of the researcher as an independent, objective observer is a myth (Barnes, 1997; Stubbs, 1999), and therefore a paradigm of emancipatory research, i.e. one that contributes to the empowerment of disabled people, is the ideal (Oliver, 1997). Disabled people need to have more control over the research process, its scope, methodology, and the dissemination of findings (Lysack and Kaufert, 1996).

The traditional perception that research is something only academics can do is now fortunately changing, with the recent development and widespread use of participatory approaches (Chambers, 1983). Initially designed with rural farming populations in mind, participatory approaches (PRA/PLA) have been adapted for use in the water and sanitation sector, e.g. PHAST (Simpson-Hebert et al, 1996), for the education sector, e.g. Actionaid's REFLECT (Archer and Cottingham, 1996). They have been used effectively with people of all ages – with elderly people (HAI, 2002b) and with children (Johnson et al, 1998). They have been used by child researchers in peri-urban areas, e.g. on child labour in Vietnam (Theis, 1998), and in squatter communities in Zimbabwe (Save the Children, 1999a). PLA has been used as a tool for discussions with community members about disability and CBR in Indonesia (Tjandrakusuma, 1995), and has been used by and with disabled adults and children in Thailand (Save the Children, *undated*) and in Angola (Harknett, 2000).

Demystification and de-institutionalisation of research are the key to empowering disabled people (Bang, 1996). 'Often disabled people have been excluded from participating in research on the basis that they are illiterate. By finding out what disabled people need and disseminating the information widely, we can begin to build up communities and maximise resources so that technology is not only available but also appropriate' (*ibid.*).

During their study of the daily lives of a group of disabled Indian women, Mulholland et al (2000) found the women had difficulties providing answers based on 'abstract supposition', about problems they may encounter, rather than on their first-hand experience. This highlights the importance of using strategies which are 'sensitive to the population's current skills and abilities'.

Research does not have to involve written documentation to be an effective advocacy tool. In Vietnam, a DPO put on a city-level exhibition of photographs they had taken, portraying both the normality of their everyday lives and the barriers they face. It was judged just as effective in providing information and influencing opinions of the public and government officials as any written report (Save the Children, 1999b).

The collection of feedback from disabled women in India used an exploratory/descriptive case study approach to collect both qualitative and quantitative data (Mulholland et al, 2000). This was developed using available literature, information from a discussion group with Indian OTs, results from an initial mobility needs assessment and input from engineers and designers in both Canada and India.

Participatory approaches are as suitable for use with disabled people as anyone else, but PLA tools may need to be adapted so that they are accessible (Yanni, 2001). Lewis (2000) provides guidelines based on experience and key lessons from Save the Children's Global CBR Review, which involved disabled and non-disabled adults and young people from CBR projects around the world. Materials are also available on approaches to working with disabled children and young people in research and development projects. Ward (1997) and Morris (1998) identify key issues, outline some strategies and provide useful checklists when consulting the views of disabled children.

3.4 Summary of relevant issues

Debates about CBR have come to focus more on issues of control and decision-making, and less on the location of activities. In other words, effective services for disabled people depend on a number of factors and principles, but there is no blue-print that applies universally. This research is likely to be relevant in a range of service delivery contexts, but is likely to be more effective where principles of disabled user consultation, and multi-sectoral collaboration are in place.

A 'comprehensive' approach to disability is advocated, which needs to include accessible and inclusive water and sanitation facilities, which are the responsibility of service providers. The literature indicates that there is a lack of information and understanding on the part of implementers, about how to go about addressing the needs of disabled people, where to start, and what can be done. Information is, firstly, not easily obtainable and secondly, not in appropriate user-friendly formats. Caution is advised in imposing foreign values and assumptions on communities. It is important to understand and build on local knowledge, skills and beliefs, and local government and community support

structures. This may be related to local perceptions of disability, or to do with cultural assumptions about roles and responsibilities of family members of different age and gender.

A gender analysis will be needed, to ensure that increased work-loads are not laid unquestioningly on women, and that the needs of disabled women and men, girls and boys are all considered and addressed.

It is also important to be aware 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. To achieve a personal aim of 'being able to contribute to the family', increased independence may be a necessary prerequisite. Or, in order to achieve a personal aim of 'feeling less different from other children', a disabled child may need to carry out similar daily tasks, such as fetching water.

The review has shown that needs assessments are widely used in services for disabled people, but it is not always clear to how disabled people and their families are involved in the process, and to what extent the issue of access to water and sanitation facilities is addressed.

Disabled people and families with disabled members should be seen not only as beneficiaries, but as potential collaborators and innovators. Strategies would be advised to ensure that disabled people are fully involved, not only in contributing data, but in selection of subjects, informing the process and advising on accessible formats. This will contribute to an increased likelihood of project effectiveness and sustainability.

Although the focus of this project is on a family-based context, the literature review included accounts from different contexts, including health and educational institutions, and disabled people displaced through conflict or disaster. These have shown that the need for access to water and sanitation is equally pressing, but that many of the issues of access that disabled people face in a stable, family environment tend to become more problematic in these circumstances.

The review identified snapshots which illustrate the wide range of geographic contexts, cultural perceptions of disability, and attitudes and behaviour towards disabled people. However it was also found that there appear to be some broad principles and processes involved in identifying and meeting the needs of disabled people, that can be applied globally.

4. Aids and adaptations

4.1   Introduction

This chapter presents a review of current, available information on the use and usability of water and sanitation by disabled people with physical limitations, in both poor rural and peri-urban situations. Sources, drawing and transportation of water are described with respect to their access. Assistive devices and technology are described with examples for water use and toilets. The theory and principles underlying assistive devices/technology and accessible environments are described. This is followed by a discussion of appropriateness and acceptability to local contexts. Where no solutions have been found, these gaps are highlighted as areas of potential further study.

It is reported that there is 'a lack of quality information about water use in rural areas, as most research has focused on the developing world's expanding urban centres and "mega-cities".' This is 'most acute for Sub-Saharan Africa – the region whose population is the most rural and has the least access to improved water supply' (Thompson et al, 2001).

A useful checklist is available for a survey of accessibility of the built environment (UNESCAP, 1995: Annex VIII).

4.2   Water sources and drawing

4.2.1 Natural, open, sources

No specific references were found relating to access for physically disabled people to lakes, rivers, streams or ponds. Solutions dealing with soft ground, steep ledges, differing water levels, and the attendant adjustable access requirements, were not found in the literature searches. Indeed, it has been stated that people with mobility impairments do not use surface water (Hollingsworth, 2001), although this statement relates to independent use, as people can be carried up to, and in to, water sources by humans or animals, or on various vehicles such as carts.

4.2.2 Wells

Wells are frequently built up above ground level for safety and hygiene reasons; this height may be a barrier to some users. Reducing the height of a well wall can increase accessibility, but needs to be balanced against the risk of people falling in (Holdsworth, 2001). The

mechanisms to lift water buckets may be one or two-handed – but with-out a lock/ratchet, a one-handed operator will have difficulty changing from raising water, to pouring water into a receptacle. A mechanical advantage is achieved by using a well rope over two pulleys, which lessens the strength required to pull up buckets of water (Helander et al, 1989: 29). In Cambodia it is reported that 'some NGOs working at grass-root level have provided accessible pump wells that can be used by people with crutches/wheelchair/ missing arms or legs' (Mony, 2002), but to date no further details are available.

4.2.3 Handpumps

A pump which has a dual-action for efficiency (raising water, for exam-ple, on both the 'up' and 'down' strokes) is more demanding of the strength and abilities of a user, than one which is operated by leaning (body weight) or pushing (or pulling) in one direction only. Some in-stances of pumps with long handles have been reported (CRP, 2002) and recommended (Helander et al, 1989: 29). The long leverage re-quires less effort and may be more reachable, but the longer handle has to be moved over a wider arc.

For a direct action hand-pump, the force required at the handle to pump the water 'may be too high for children, especially when the water table is deeper than 5m' (Brikké, 2000). For a deep-well piston hand-pump, the force required to turn the handle of the pump may be high (ibid.). Literature on rope pumps have not been found to comment on their ease of use by physically disabled people; for example there is no men-tion of this in detailed documents such as 'The Rope Pump: Private Sector Technology Transfer from Nicaragua to Ghana' (WSP, 2001).

To avoid the difficulty of pumping and holding a container at the same time, a suggested solution is for a large container to be placed beneath the pump, which is then accessed via a tap at its bottom (Holdsworth, 2001).

4.2.4 Tap stands

No specific references were found regarding the use of tap stands (pub-lic or private) by physically disabled people, although the operation of a tap can be eased by an extension handle that fits over or onto the tap, commonly made of wood or bamboo (Van der Hulst et al, 1993).

4.2.5 Rainwater collection

No specific references were found relating to access for physically disabled people to collected rainwater.

4.3　Water transportation

The physical effort required to collect and transport water makes distance a significant barrier for physically disabled people. Appropriate equipment to lessen the effort can be used to increase carrying range and capacity. A pole can be used to make a yoke, worn on the shoulders, to carry buckets of water attached to each end (Helander et al, 1989, 29). For people using human powered tricycles or carts, a wheelchair carrier has been developed for disabled women to carry water (Musenyente, 2002). Water can be carried on a trolley with a wider than normal base to accommodate a water vessel (Mulholland et al, 2000), or using a piece of wood with holes to ensure that containers stay in place (Helander et al, 1989: 29). Where these vehicles are only used outdoors, they do not need a maximum width restriction (as would be necessary to pass through doorways) and thus can be more stable from tipping sideways, and can be constructed to carry greater loads.

A physically disabled person may also be able to use animals, such as donkeys, horses, bullocks or buffalo, to carry water or pull carts carrying water (Helander et al, 1989: 29).

Disabled people at CRP in Bangladesh suggest that tube-wells should be set up near their living place, and making the road to their homes more even would make it easier for them to collect water (CRP, 2002).

4.4　Water storage

No literature was found about the transfer of water from its delivery to smaller storage vessels inside the home, or access to personal water storage by physically disabled people, although this is common practice throughout Africa and Asia where there is no piped supply into homes.

4.5　Access and use of water

Many household activities, including bathing, laundry and food preparation are, in many rural communities, conducted on the ground (Mulholland et al, 1998), where a traditionally configured wheelchair would isolate the user from the family. This working arrangement is not static;

when washing clothes and cooking, objects are carried about. A solution to this common need for low-level access is a 'low-rider' wheelchair or trolley 'to meet village women's need to cook and eat at ground level' (Mulholland et al, 2000; Werner, 1998). This would need to be matched with low-level water access to enhance the contribution that can be made by the low-rider user. There are 'many indigenous low height designs' of mobility devices, although their existence and evaluation are not circulated effectively (Mulholland et al, 2000).

Van der Hulst et al (1993) provide illustrations of examples of simple personal aids for disabled people in daily life: devices for operating taps, bathing and toileting. Although the range is not extensive, the examples can inspire new appropriate devices and solutions (Table 1.5). The Society of Hidden Talents in Uganda has developed in model form a number of affordable assistive devices from local materials, such as an adaptable dish rack, toothbrush stands for cleaning teeth without holding the brush, etc. (Musenyente, 2002).

Table 1.5 Arrangements and assistive devices for water use

ARRANGEMENTS AND ASSISTIVE DEVICES FOR WATER USE	
Task	Solution & Reference
Bathing – infra-structure.	Those with poor sitting balance: sitting in used inner tyre tube, or rope support in a pond or stream (Werner, 1987: 346; Musenyente, 2002). Low seat/stool/box for those unable to stand or squat whilst bathing (Werner, 1987: 346; Musenyente, 2002). Handrail of bamboo/rope/string can provide guidance for a blind person to get to bathing place (Helander et al, 1989: 2). Washing platform of wooden or bamboo slats for those who wash lying down (Werner, 1987: 346). Recommendations for design of shower cubicles, wash basins for wheelchair users (UNESCAP, 1995a: Annex II). Commode chair with hole cut out makes it easier to wash buttocks and genitals when seated (WHO, 1996b: 65).
Bathing – individual aids.	A wash mitt, like a glove made from a piece of towel, for those with poor grip (WHO, 1993, 1996b, 1999; Werner, 1987: 347). Long-handled sponge or brush or towel with loop handles, for those with limited range of movement (WHO, 1996b: 67; UNDP, 1996: 43; Van der Hulst et al, 1993). 'Soap on a rope', shampoo in a squeeze bottle and a small scoop or saucepan (WHO, 1996b: 66).

Teeth cleaning, cleaning nails.	Toothbrush stand for those unable to hold toothbrush (Musenyente, 2002). Hand-grips for toothbrush/ tooth-twig, as for spoon grips (Werner, 1987: 330; WHO, 1996b: 63). Nail brush with suction cups (UNDP,1996: 46).
Clothes/dish/ food washing.	Laundry can be washed at a table or on a large stone from a seated or standing position (Helander et al, 1989: 29). Accessible laundry facilities, with knee space under sink/trough for a seated person (Werner, 1987: 488). Recommendations for design and layout of kitchen facilities for wheelchair users (UNESCAP, 1995a: Annex II).
Drinking.	Cup with two handles, cup holder, or use of a straw or hollow stem can help those with weak hands to drink (Helander et al, 1989: 14; Van der Hulst et al, 1993; Werner, 1987: 329; WHO, 1996b: 61, 1999: 99, 103). Plastic cup with cut-away rim, for a child with cerebral palsy to drink without tipping head back (Werner, 1987, p.326). Non-spill cup holder to prevent tipping (Werner, 1987, p.330; UNDP, 1996, p.32). Cup holder from woven grass or cane or wood for hot drinks, especially suitable for people with no feeling in hands (Helander et al, 1989: 18).
Using utensils, for food preparation, cooking and eating.	Bamboo, cane or cloth, or other material wrapped around handles, can make utensils - spoons, knives, forks, etc, easier to hold (Helander et al, 1989: 29; Van der Hulst et al, 1993; WHO, 1996a, 1999). Thick handles make pots easier to lift; wood, cane or bamboo can protect from burns (Helander et al, 1989: 18).
Household cleaning.	For those unable to carry, or bend down – long-handled tools for housework: long handled mobile mop and bucket stand (UNDP, 1996: 69).

4.6   Access and use of sanitation facilities

4.6.1 Toilets and latrines

WHO (1996b) recommend that where possible, toilet and bathing facilities be located in the same room, for ease of use by a disabled person. In such a situation, the latrine is often raised slightly, to prevent materials from falling in; this step or slope can hinder ease of use for physically disabled people. The removal of footpads from around a squat

toilet can permit easier location of a wheelchair over the hole (Hollingsworth, 2001).

Because the bins of composting toilets are generally installed at ground level, the toilet enclosure is elevated and stairs or ramps are required for access, this could be a problem for elderly and disabled people. One solution is to build a house with an elevated veranda area, under which the bins can be stored (UNEP, 2000).

4.6.2 Alternatives to toilets and latrines

A large proportion of the rural population uses either inadequate pit latrines or the flat open grassland, leading to constant infection and re-infection of rivers and streams (Hemson, 2000). A range of tool adaptations for disabled workers are available that can be used for burying excreta, so that run-off pollution is minimised (Dilli, 1997), for example a trowel or spade with a long handle that is further supported by the user's arm.

Table 1.6 Arrangements and assistive devices for toilets/ latrines

ARRANGEMENTS AND ASSISTIVE DEVICES FOR TOILETS	
Requirement	Solution & reference
Adaptations to a sitting toilet.	Guidelines on design of accessible Ventilated Improved Pit toilets for disabled users, including turning room for wheelchairs (Deverill and Still, 1998). Guidelines and design specifications for toilets, e.g. space requirements, sliding/outward opening door (UNESCAP, 1995 Annex II). Rail beside toilet, handles on the wall, or frame around toilet will help to transfer on and off toilet (WHO, 1996b, 1999; Werner, 1987: 342). Padded toilet seat, or tyre inner tube, reduce risk of pressure sores (WHO, 1996b; Werner, 1987: 344). Raised toilet seat for those with difficulty sitting down/getting up (Van der Hulst et al, 1993).

Adaptations for a squat toilet.	For those unable to squat, a commode made from a wooden chair, box, wedge shape, etc. with a hole cut out can be placed over the hole (Van der Hulst et al, 1993; Werner, 1987: 342; WHO, 1996a, 1999: 94). For a young child, a corner seat or wooden wedge with a hole, or even two bricks, can form a makeshift seat (WHO, 1993). Squat toilets can be made wheelchair friendly by installing a fixed commode with space next to it to transfer from the wheel chair. A wheelchair can have a seat opening for non-transfer bowel evacuation when placed over latrine hole (Werner, 1987: 343). Removed footpads to allow toilet seat/wheelchair to be positioned over latrine (Holdsworth, 2001: 30). Wheelchair with hole cut in 'jump seat' – transfer seat half way between seat and ground (Werner, 1998: 193). Foldable toilet seat with arm rests that can be placed over hole, and folded away when not in use (Balaram, 2001). A seat with a hole attached to the wall with a hinge, can fold-down over the hole. Non-slip squatting plate (UNDP, 1996: 54).
Aids for balance/ guidance.	Handrails/handles or rope handles (either vertical or horizontal) at sides or front of toilet can help balance (Helander et al, 1989: 14; Kiwanuka, 2002; UNDP, 1996: 56-7; Werner, 1987, 342; WHO, 1996a, 1999: 93). A walking frame can be placed around the toilet (WHO, 1999: 93). Recommendations for installing 'grab-bars' (UNESCAP, 1995a, Annex 2). A fixed string or rope can be used by a blind person as guidance to toilet facility (Helander et al, 1989: 2; Nieman and Jacob, 2000: 82). A potty placed inside an upturned table or chair can help a young child with poor sitting balance (WHO, 1993: 69).
Personal hygiene.	Toilet paper tongs for people with gripping problems (UNDP, 1996: 57). Wooden handles to assist disabled people crawling in unhygienic places (Musenyente, 2002).

Alternatives to toilet/ latrine.	A commode can be built-in to a wheelchair, with a cushion placed over the hole for ordinary sitting (Werner, 1998: 15; WHO, 1996b).
	Low-level trolley with commode base; tyre inner tube serves as both cushion and toilet seat (CRP, 2002; Werner, 1998).
	Portable child toilets can be made from wood, bamboo, old car tyres, old plastic buckets, converted from wooden chairs (Caston, 1982; Werner, 1987; 344).
	Mobile toilet – walking frame with a fold down potty seat (Werner, 1998: 214).
	Various proprietary commode seats (UNDP, 1996: 54-55).

4.7   Access and use of refuse disposal

No reference was found relating to refuse receptacles in poor, urban or rural contexts. This may be because there are no formal refuse collection services in rural communities where waste is often used for fires or feeding livestock. However, the need to develop more user-friendly, easy to use, waste and recycling bins has been identified as an issue in Europe, where 'the design of current waste bins, paper and bottle banks presents barriers for disabled and elderly people' (Jensen and Woetmann, 2001). No references were found with regards to basic universal design criteria relating to refuse disposal in slum settlements.

4.8   Accessible environments and assistive devices

There are two primary options for achieving the goal of disabled people's activity and participation in the wider environment. Firstly, the adaptation of the physical environment to allow access for people with a wider range of needs and functional limitations than is currently considered the norm, and secondly, appropriate Assistive Technology/ Devices to enable an individual user to access the current physical environment (UNESCAP, 1997). Human assistance is the coping strategy of many physically disabled people, so better provision of accessible environments and assistive technology can reduce reliance on human assistance, and promote personal independence and dignity. Independence and interdependence are, however, cultural concepts which need exploring in different contexts.

4.8.1 Assistive devices / technology

Assistive Technology (AT) has been defined as 'any item, piece of equipment, or product system, whether acquired commercially or off the

shelf, modified, or customised, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities' (US 'Technology-related assistance of individuals with disabilities act', 1988, PI 100-407, quoted in Scherer, 2002).

The purpose of AT is to facilitate or enable the performance of activities of daily living (Mulholland et al, 1998). For many with disabilities, assistive devices (AD) are a basic need as important as adequate shelter, and international and national mandates concerning them have been published and are available (UNESCAP, 1997).

There are three forms of assistive devices – those that are carried (personal), those that are fixed for personal use and those that are fixed for public (communal) use.

4.8.2 Universal Design

In the past, designers and providers of the built environment have considered only the needs of the fit and healthy with slight regard for the wider range of the population, this results in the unintentional creation of barriers of many forms, especially for elderly and disabled people (UNESCAP, 1995a).

An alternative approach to dealing with barriers is that promoted by Universal Design, which is guided by the 'Seven Principles of Universal Design': equitable use, flexibility in use, simple and intuitive use, perceptible information, tolerance for error, low physical effort, size and space for approach and use (Center for Universal Design, 1997).

Universal Design 'should allow for a wide variety of human operation styles' in order to serve users with different abilities (Story, 2001). An important design consideration is that 'by incorporating the characteristics necessary for people with physical limitations into the design of common products and building spaces, we can make them easier and safer for everyone to use' (Mace, 1990).

More recently, many designers have adopted the ideal of Inclusive Design (design to include all) that considers a wider range of users, and places more importance on considerations of personal dignity (UKIID website).

Universal Design and Inclusive Design both take a holistic view of problems and potential solutions. Good design of the built environment ensures that there are less barriers, and those barriers that do exist are more easily dealt with, this in turn reduces the frequency of use, and

even necessity for ADs. An accessible physical environment, and provision of AD/T form complementary components that contribute to making particular tasks achievable.

4.9 Approaches suitable for people with physical limitations as a result of other impairments

Rehabilitation practitioners such as occupational therapists, physiotherapists and CBR workers are trained to work with disabled people using a supportive problem-solving approach. Their role is to help analyse the difficulty, give information and suggestions and support the disabled person in decisions to find solutions. Teachers with special needs training also give advice and support to parents in teaching children independent living skills. Parent support groups are also helpful in passing on experience and information.

Children and learning difficulties

A range of materials are available that provide advice on teaching approaches for children with learning difficulties. Well-known examples are Portage and its adaptations (e.g. Zaman and Munir, 1990), parts of the WHO training manual (Helander et al, 1989) and others (Baine, 1990; Thorburn, 1990b; Werner, 1987). Advice is available for social workers in supporting families with a disabled child (Jackson, 1993).

Children with developmental delay or learning difficulties may have problems with balance and physical co-ordination. Some design and AD solutions to this have been suggested in Sections 4.5 and 4.6. In addition, problems with learning and remembering how to carry out ADL can be reduced by the way facilities are physically arranged: consistency is important, and objects used for a particular daily task should be kept in the same easily accessible place, on view.

People with dementia:

Advice for carers of a person with dementia emphasises the importance of avoiding confusion, maintaining regular routines, and keeping things simple (ADI, 1999b). Arrangement of the physical environment can contribute to simplifying everyday tasks, by ensuring that objects are kept in familiar places, and on view – on shelves or hung on hooks, rather than tidied away in drawers.

For supporting blind children to learn ADL, the literature emphasises that they should be treated no differently to others, and that no special equipment is needed. There is acknowledgement however, that planned teaching may be needed of activities that other children pick up by observation, and that order and consistency in the physical environment can help with orientation (Horton, *undated*). Manuals such as `Helping Children who are Blind' (Nieman and Jacob, 2000), 'Community-based rehabilitation of the rural blind' (Horton, *undated*) and Section 2 of the WHO CBR Manual: Training package for a family member who has difficulty seeing' (Helander et al, 1989: 2) focus on teaching mobility and orientation, and ADL. Keeping things always in the same place helps the blind person with orientation, and fixing a rail or rope can provide guidance, e.g. to a latrine or bathing spot. Protection on the edges of ramps, verandas etc. with a raised kerb or rail is also necessary.

4.9.1 Human assistance

The most widespread aid for physically disabled people is the human assistance rendered by family, friends and the local community. 'Family is the core point of helping disabled people if the [CBR] field worker can motivate/ encourage them' (Mony, 2002). In some cultures it is the norm for the disabled person to be dependent and no-one is aware of an alternative. A concept of independence and its benefits may need to be discussed in a way that is empowering with the disabled person and their carers. Families may need to be encouraged to allow or stimulate the disabled person to be more independent.

4.10 Issues of appropriateness

Much of the literature raises issues of appropriateness (Thorburn et al, 1990; Werner, 1987, 1998). Key issues to be borne in mind are:

- ***Cost and affordability.*** This is a major barrier for the majority. In poorer areas where family members are always on hand, local practice maintains that it is more viable for a person to be carried about than to invest in ADs. Situations such as these must only improve over time, as accessibility is demonstrated to be achievable by the simplest of means, at minimal cost or effort (Harrison and Parker, 2000).

- ***Locally available resources and materials***: An appropriate technology solution should use local materials and human resources (Mulholland et al, 2000; Thorburn et al, 1990). The Assistive Device

Network (ADNet) in Bangladesh brings together GOs and NGOs with the aim of supporting disabled people through the use of ADs, some of which are used in ADL, and adaptation of homes. The network promotes local adaptation of designs using indigenous materials (Borg, 1998). For the poor, cost is a critical criteria and solutions using readily available, very low-cost, materials are preferable – e.g. old tyre inner tubes, bamboo, etc.

- ***Cultural acceptability.*** This is a combination of aesthetics, image and personal dignity. 'Appropriate assistive technology doesn't have to mean cardboard seats and tire tread sandals' (Enders, 1998). A wheelchair adapted to a self-propelled prone trolley was rejected by a patient with a spinal cord injury, even though it worked well, because it portrayed the image of a peasant device (Werner, 1987). Many a solution has been found to be inappropriate, as it did not fulfil the necessary criteria of cultural appropriateness, home context and sustaining the user's dignity (Thorburn et al, 1990a; Van Brakel and Anderson, 1998).

- ***Local beliefs and attitudes:*** may not support personal independence and self-reliance. 'Cross-cultural biases (urban-rural) and unquestioned assumptions are only compounded by ethnic and socio-economic differences' (Enders, 1998). Thus solutions based on generic principles need a strong element of local context and user feedback, to meet the social and cultural living set-up.

- ***Gender appropriateness.*** This is an important, though little reported, consideration. For example it is important that a woman's need for cradling an infant whilst stooping to collect water is taken into consideration (Wahab, 1997). In a study in India, women with lower extremity disabilities were reported to clearly identify activities they wished to perform if they could move more easily, a clear example of improved independence and quality of life through improved mobility through the application of effective assistive devices (Mulholland et al, 1998).

4.11 Summary of relevant issues

There is a lack of information regarding access to water sources and drawing equipment and practices, in terms of their ease of use by people with different abilities and strengths. There is information regarding transporting water, but not including storage within dwellings, and little attention has been given to household refuse systems for people with physical disabilities.

There is information available regarding gender issues and the additional burdens often imposed upon women, but the problems encoun-

tered by, and potential enabling solutions for, women with physical disabilities are largely ignored.

The information that has been found seems to exist in isolated pockets, almost invariably associated with a particular set of circumstances (such as user requirements, location) as a local 'fix' to a problem. Procedures and adaptations for cooking, washing and toileting appear to be 'discovered' locally to meet specific needs. These solutions primarily use local materials and skills, tempered by low cost.

There are a few documents that are widely available, e.g. Werner (1987, 1998), and WHO materials. More local solutions, whilst often highly effective for particular users in their personal circumstances, are rarely publicised or fed back for the benefit of others, even at a country or regional level.

The consensus appears to be that a combination of approaches – accessible environment + assistive technology – is the ideal and that it is more cost-effective to incorporate the needs of all users from the outset when providing services, rather than update, or add-on, facilities to make them inclusive at a later date. Solutions must be affordable, appropriate and acceptable, using local resources, flexible and optimised to meet the needs and preferences of the end users.

In spite of the lack of information, it is fair to conclude that some of the principles of appropriate technology and equipment are universal, but local cultural perceptions and norms mean that designs need to be adapted to suit local circumstances.

5. Community and disability

As established in Chapter 2, it is generally accepted that the knowledge, understanding, and above all behaviour of non-disabled people can be pivotal to helping or hindering disabled people's opportunities for participation.

In the field of international development, many organisations have long considered that communication is central to their work (e.g. Oxfam, 1999; Healthlink Worldwide, 2002). They recognise that direct implementation of projects will only have a limited impact, unless they treat advocacy as 'an integral part of their work, [which] creates the potential to influence change on a much wider scale' (Save the Children, 2000b).

5.1 Disability awareness-raising

In the field of disability, advocacy and awareness-raising is a widespread complementary strategy to practical service/project implementation, not only at community level, but also among government and service providers (Radda Barnen et al, 1998; Sachelo, 2002; UNESCAP, 1995a).

Gunnarson (1998) describes a project in Ethiopia which provides direct support to families, but also works to combat negative attitudes of the community: through drama and music at community meetings, and workshops for school students, with the intention that they then disseminate this knowledge to their classmates, families and neighbours.

At community level, 'awareness-raising' is routinely included in skills training workshops, as project implementers realise that knowledge and skills development is often a waste of time if participants do not recognise the need to apply the skills learnt (Jones, 1999a). In projects promoting inclusive education for disabled children, for example, Save the Children/Sweden and UK implement both skills training and disability awareness for teachers (Save the Children, 2002a). In Vietnam for example, discussion groups are held for teachers to discuss disability, with the result that teachers are less negative about accepting disabled children in their class (Gunnarson, 1998).

5.1.1 Approaches to disability awareness raising

A commonly used activity in disability awareness training is 'disability simulation', where participants are asked to perform activities whilst

temporarily 'disabled' – blindfolded, sat in a wheelchair, wearing ear-plugs, etc. This approach is opposed by many disabled critics, because of the focus on the individual impairment, and for leaving participants feeling helpless and confused. This makes them feel pity for disabled people, rather than the desired respect and understanding (French, 1996; Linton and various, 2002). Some commentators do concede that carefully designed task-focused exercises can serve a useful purpose:

> 'When the exercises are designed to teach global lessons about the disability experience I think they are misguided and offensive. BUT, I have recently been thinking that there are some very specific, practical lessons that a targeted exercise can deliver. For instance, architects should have the opportunity to experience what the real turning radius of a wheelchair …is, or slopes of ramps.' (Linton, 2002).

In the UK, the most common form of training on disability issues is Disability Equality Training (DET), which is designed and delivered by trained disabled people. The aims are 'to enable participants to understand disability from a social model perspective and to commit to removing disabling barriers' (DET, 2002). The main difference between DET and disability 'awareness-raising' seems to be that DET is rights- and action- based, whereas much 'awareness-raising' focuses on improving the understanding, empathy and individual goodwill of participants. 'Making people aware of their own prejudices is not enough. What is needed is training in how discrimination against disabled people can be prevented or dismantled… and how disabled people are affected by discriminatory practices' (French, 1996).

5.1.2 Cultural appropriateness

Issues of cultural appropriateness are especially pertinent here. It is important to identify and understand existing cultural beliefs, in order to be able to design culturally appropriate messages (Wong and Subramaniam, 2002), and to build on positive aspects and strengths (Jones, 1999a; Miles, 1995).

A number of writers provide accounts of positive aspects of local cultural views of disabled people. In Sri Lanka it is reported that 'sympathy and kindness towards the disabled is a social tradition' (Siriwardane, 1997). In Tanzania, Kisanji (1995a) finds few instances of traditional proverbs which portray negative or rejecting attitudes to disability, and Miles (2000) points out different 'models' of disability in Asian historical context.

Where negative beliefs are prevalent, providing accurate information about particular impairments can counteract misconceptions, which is particularly important in the case of stigmatised conditions such as leprosy or epilepsy. It is acknowledged that misconceptions are difficult to dispel (Wong and Subramaniam, 2002), and it is suggested that it is better to 'work around' misconceptions, rather than try to denounce them outright.

5.1.3 Role of media/information

The role of media in information dissemination cannot be overlooked (DAA, 1993). In Uganda, a seminar was held for journalists about disability issues and the use of appropriate language, which resulted in a regular disability column in a national newspaper (Kangere, 1997). The Nepal Human Rights Disabled Centre held a workshop in 2002 on the role of the media, led by a disabled journalist, for all major national stakeholder organisations. A series of radio programmes has since been broadcast on national radio, a magazine is produced for sale and a telephone help-line is planned, which will be a pioneering initiative (Payne, 2002).

Radio programmes are beginning to be made on disability issues as in Uganda (Payne 2002), and Viet Nam (Save the Children, 2002b) which are an affordable and accessible media for the majority.

A help-line for parents of disabled children has been set up in India, by Asha, an NGO, working in the Delhi slums. Asha has also taken a leading role in combining the efforts of a range of organisations, around the need for effective communication of information on disability. The group felt a particular need to publicise services that were putting into practice national legislation (Payne 2002).

A lack of information exists in many countries that may have model national legislation, such as Zimbabwe, but which is not implemented. Widespread awareness will help bring pressure to bear on services (Mlotshwa, 2000).

In Sri Lanka, the Swedish agency SHIA takes a comprehensive approach. This includes support for DPOs, for CBR, and for income generation projects, and awareness programmes to educate the media, business community and general public, on the rights of people with disabilities, their problems and abilities (Siriwardane, 1997).

Electronic media is playing an increasingly important role, and could be exploited more for international information sharing. A regular informa-

tion bulletin is distributed by email from Bangladesh by Centre for Services and Information on Disability (csid@bangla.net). From the US a substantial E-zine is produced by Disability World (see list of websites).

Videos are very effective and television, audio-cassette and Braille make information more accessible, not only for visually impaired people but to non-literate people.

While newsletters, manuals and booklets are frequently produced by disability organisations, the impact is frequently not evaluated. Initial information needs assessment and tools to evaluate effectiveness are necessary. The distribution of materials is not given enough importance. Information resource centres are being set up in low-income countries with a growing move among Northern agencies in the field, such as Healthlink and EENET, to collaborate in supporting new resource centres.

5.1.4 Role of key stakeholders

Disabled people are the key to changing attitudes and behaviour. They are the experts, they can act as role models, and can motivate children and parents (Kangere, 1997). For some non-disabled people, the opportunity to meet a disabled person and interact with them on an equal basis can be a real eye-opener, and is highly recommended by disabled trainers (Martinez, 1997; Rieser, 1995). An alternative is to give disabled children and adults opportunities to present their perspective through different media. In Vietnam, a group of disabled adults presented an exhibition of their own photography portraying their lives (Save the Children, 1999b), and a weekly radio programme gave disabled children the opportunity to share their views, get advice and to explain about the barriers they face in everyday life (Save the Children, 2002b).

In low-income communities, DPOs are increasingly active in promoting attitude change. In Zambia, DPOs have come up with programmes on the rights of people with disabilities, to educate community members to accept people with disabilities as equal partners, who have the right to participate in all community activities (Sachelo, 2002). Parents can also take a key role in promoting the rights and interests of their disabled children (DICAG, 2002; Mphole, 2000).

DPOs may initially need support to enable them to carry out such activities. In Thailand, UNESCAP held a one week workshop, to develop materials to support disabled people to become trainers and advocates on disability issues in the ESCAP region (Parker, 2001).

Uganda is highlighted as unusually accepting of disabled people (May-Teerink, 1999). Suggested reasons for this are a high prevalence of disability, so that non-disabled people frequently encounter disabled people, a very active national DPO, and disabled people as members of parliament, who provide high profile successful role models.

While information is a right, it also involves responsibility. All those privileged to have information have a responsibility to pass it on in accessible formats. There is a need for information to be communicated more from South to North, and for South-South exchanges to promote shared learning.

5.1.5 Useful materials

Many NGOs are producing printed materials such as newsletters, booklets, posters to raise awareness of disability issues, and available services. The UK-based Disability Awareness in Action produces a series of Resource Kits for DPOs to use, on issues such as Campaigns, Media Information, Civil Rights Law and Disabled People (DAA and Independent Living).

Healthlink Worldwide, UK, works in disability information and communication in various low-income countries, producing manuals and a newsletter, Disability Dialogue. These publications are adapted and translated in partnership with local organisations, including DPOs, with an estimated readership of over 100,000 globally. The aim is to share practical accessible information suited to the local context, and distributed at low cost or no cost. Directories of disability materials are produced based on a collection at Source, the international information support centre at the Centre for International Child Health, London (Payne, 2002).

Similar information networks are Enabling Education Network (EENET), which promotes South-South and South-North communication on issues of inclusive education, and Child Rights Information Network (CRIN), which shares information on child rights globally.

A number of free newsletters exist on disability (Healthlink, 2001). Some of these, like Disability Dialogue (formerly CBR News), in turn often signpost other useful resources. One issue of CBR News had several articles on working with the media (e.g. Phiri, 1998), describing existing good practice and providing concrete training ideas. A useful resource aimed at a community-level, Including Disabled People in Everyday Life is flexible enough to be used with any community from the UK to Cambodia (Jones, 1999a).

5.1.6 Alternative formats

Written formats are not always the most effective, especially in cultures with a strong oral tradition or with low literacy rates. Pictures can be used: an unusual cartoon booklet on accessibility has been produced by an NGO in Brazil, illustrating the problems faced by a young wheel-chair-user in her daily life, and the benefits of accessible facilities (Resende and da Silva, 2000). Drama and song can also be powerful in communicating messages. The Child-to-Child approach to communication about health has always used a variety of media to promote active learning among children, including role-play, games, posters, songs and drama (Bailey, 1994). Learning about disability, its causes and prevention, including land-mine awareness, and attitudes and behaviour to promote the inclusion of disabled children, are issues covered by Child-to-Child (Hanbury, 2002).

5.2 Summary of relevant issues

Addressing attitudes and behaviour change are a vital element in strategies to improve disability access, and when implemented alongside practical work, each can increase the effectiveness and impact of the other.

A wide range of advocacy and awareness-raising initiatives to address social and institutional barriers, are being implemented and documented by a variety of agencies, including local DPOs, INGOs and bi-lateral agencies.

A focus simply on awareness-raising is not enough; efforts need to extend to addressing practical actions and changes that people can undertake in their work and community.

It is important, however, to take into consideration local cultural beliefs and practices, in order to build on positive elements, and to identify locally appropriate solutions.

Disabled people need to be consulted and at the forefront of strategies for change as far as possible, and be supported to develop the skills to be able to do this. This means that this project needs to ensure that disabled people are involved, not only in providing information, but in planning further research, especially field-work, in deciding what information would be useful, and in what formats, in field-testing and providing feedback on outputs, and in dissemination of results.

The need for widespread dissemination of available information using all available means, including a variety of formats and media, is perhaps the main challenge for this project.

6. Conclusions

The purpose of this literature review was to establish whether or not there is a need for the planned research, to verify that we are not duplicating existing efforts, to highlight gaps in information, and to identify existing knowledge and practice that this research can build on.

An extensive amount of information from a range of relevant fields has been identified and reviewed. 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 of it was irrelevant to low-income communities. This is because it was either only applicable in modern urban environments, or assumed a high level of available resources and expertise.

There is a growing body of literature about and by disabled people in low-income communities in general, the problems they face, and approaches to working for their benefit. Much of the discussion was found to be relevant to this research. Information from practitioners in the field has been some of the most valuable. Only a small proportion of the literature, however, specifically mentions issues related to water and sanitation, and almost always in the context of describing activities of daily living. Practical solutions are largely based on an individual problem-solving approach. Patterns and principles for universal design can be drawn from these as a guide rather than a blue-print.

On the 'hardware' side, a search of the disability-focused literature found most detail related to activities of toileting, hygiene and self care, fewer references to household activities using water, and only one or two references to fetching and carrying water.

A search of the technical literature, in the fields of water and sanitation provision, found very little mention of access for disabled people. A problem arose in searching databases, as the term 'access' is widely used to refer to the *provision* of water and sanitation, rather than the *usability/ accessibility* of water and sanitation facilities, so a high volume of irrelevant literature was brought up and had to be sifted through.

No claim is made to have identified all the relevant literature, but enough has been found to be able to judge where there are significant gaps in information, and to identify salient issues that have a bearing on this research.

6.1 Gaps in information

Most information collected described the difficulties faced by disabled people, and only very few gave examples of good practice. Those that were identified tended to provide only a general description, and it has been difficult to find out more concrete and detailed information. Even where the authors knew that information exists, it was not always possible to obtain it in the time available.

A number of areas were identified where little or no information was found. These were largely in technical areas related to:
- Ways to improve access to natural open water sources.
- Ways to improve access and usability of wells, hand-pumps, tap stands, rainwater collection systems.
- Transportation of water.
- Storage of water, access to stored water.
- Accessibility of household refuse disposal systems.

There are several likely reasons for these gaps:
a) These are areas in which nothing has been done and no information exists.
b) Knowledge and information exists, but is not written down.
c) Information is written down, but in languages other than English.

Anecdotal evidence and the authors' personal experience suggest that b) is the most likely – that information exists, but is not written down, and therefore a desk-based review, which is limited to written information, has not been able to find it.

Particularly disappointing, although not entirely unexpected, has been the lack of response to calls for information from water and sanitation professionals.

Recommendations:

- Efforts to identify and document relevant information need to continue for the duration of the project, through relevant networks, through observation and face-to-face communication on field visits, and other opportunities for information sharing.

- In view of the lack of response from water and sanitation professionals, strategies will need to be identified to raise interest among this target group.

6.2 Holistic view of barriers

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

The review found that a wide range of advocacy and awareness-raising initiatives to address social and institutional barriers are being implemented and documented by other agencies.

Recommendations:

- The project will need to decide whether or not, and in what way the project should address these broader social and institutional issues. It is recommended that at the very least, the research will need to stay abreast of work in this field, in order to complement rather than duplicate efforts.

- The project may need to consider how outputs can provide ways of making links with and tap into existing initiatives.

- Outputs that target agencies working towards attitude and behaviour change may be considered useful, by providing examples of its relevance to issues of water and sanitation, and practical ideas for implementing change.

6.3 Broadening the target audience

The original project proposal focuses largely on outputs aimed at organisations working with disabled people and their families, concerned with aids and techniques that provide individual solutions. It is clear from this literature review that remedying individual functional limitations is only one element of a 'comprehensive' approach, which also needs to include accessible and inclusive facilities. The latter are the responsibility of providers of water and sanitation facilities.

Increasing importance is being placed by governments on addressing disability issues as part of mainstream development projects; as yet, however, there appears to be little change in practice. The review indicates that there is a lack of information and understanding on the part of implementers about how to go about addressing the needs of disabled people, where to start, and what can be done.

Recommendations:

- The research will need to consider whether project outputs could provide information and tools for practitioners, including engineers, who wish to start to address the needs of disabled people in water and sanitation projects, and if so, how it could be done. To increase the diversity of target audience would present a challenge, and a flexible format would be needed in order to suit the differing needs of a wider audience.

- It is not suggested that outputs include advocacy tools for main-streaming, i.e. materials for use in persuading those who are not interested.

6.4 Key role of disabled people

The original research proposal identifies a role for disabled people primarily as beneficiaries, whose role would be to provide the required information, and then to receive appropriate assistance. All the literature, however, points to the importance of ensuring that disabled people take a leading role in all issues that concern them. This has been shown to improve both the effectiveness and sustainability of projects.

Recommendation:

- Since the goal of this research is to improve the well-being of disabled people, the process of the research should therefore also contribute to this. It is recommended that the project consider how to consult and involve representatives of disabled people at different stages in the research: planning, field work, data analysis, and dissemination of outputs.

6.5 Lack of resources and information for practitioners

The review findings indicate that practitioners wanting to improve 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.

Recommendations:

- The research will need to identify the kind of information that practitioners would find useful, whether a single format will suit the various audiences to be targeted, or whether different formats are likely

to be needed by different sectors – e.g. engineers, therapists, disabled people's organisations. A field-testing strategy should be considered to determine appropriate format, language, and whether regional versions are needed.

- Equally important will be to identify effective dissemination strategies. Electronic formats have many advantages, but they do not suit everyone, so alternative dissemination paths must be considered.

6.6 Project scope: displacement/institutions/geography

Although the focus of this project is on a family-based context, the literature review included accounts from different contexts, including health and educational institutions, and disabled people displaced through conflict or disaster. These have shown that the need for access to water and sanitation is equally pressing, but that many of the issues of access that disabled people face in a stable, family environment tend to become more problematic in these circumstances.

The review identified snapshots which illustrate a range of geographic contexts, cultural perceptions of disability, and attitudes and behaviour towards disabled people. However there also appear to be some broad principles and processes involved in identifying and meeting the needs of disabled people, that can be applied globally.

In spite of the lack of information, it is fair to conclude that some of the principles of appropriate technology and equipment are universal, although local cultural perceptions and social norms may require designs to be adapted to suit local circumstances.

Recommendations:

- The project will need to consider how to handle non family-based contexts, such as institutions, conflicts or disaster settings. Although many of the outputs are likely to be equally applicable in these contexts, the project will need to clarify how far outputs could address the particular and unique issues that arise from each of these specific contexts.

- The project will need to consider how realistic it is to aim to produce outputs with relevance to disabled people globally. The challenge will be to strike a balance between the local and the universal. It may be realistic to apply a broad process-based framework in such

a way as to encourage the development of local solutions and adaptations.

- Generic examples of appropriate technology and equipment are likely to be useful as a basis for identifying local solutions. By contrast, it might also be useful for the project to identify and document specific examples of local adaptations, and their uses, as examples to encourage local experimentation.

6.7 The relevance of independence as a goal

The overall goal of this research is the improvement in well-being of the rural and urban poor. One key aspect of this is to promote the independence of disabled people, which would relieve the burden on families, thus allowing improvements in the economic situation of the family. One issue to emerge from the literature review, however, 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. To achieve a personal aim of 'being able to contribute to the family', increased independence may be a necessary prerequisite. Or, in order to achieve a personal aim of 'feeling less different from other children', a disabled child may need to carry out similar daily tasks, such as fetching water.

The review has shown that needs assessments are widely used in services for disabled people, but it is not always clear to what extent disabled people and their families are involved in the process, and to what extent the issue of access to water and sanitation facilities is addressed.

Recommendations:

- The project may need to re-examine the assumption that personal independence is a primary motivation for all, and that the greatest impact on family well-being is through economic improvement.

- The project may need to take a step backwards in the process of needs identification, and start by supporting the disabled person and their family to identify their own priority needs and aims, which may be based on other aspirations, such as improved self-esteem, improved health, etc. This would normally be done through a needs assessment.

- The project will need to consider whether or not a broad-based needs assessment should be part of its remit. If it is decided that it is not, the project will need to consider what tools might contribute to those whose job it is to carry out such an assessment, to help them address issues of access to water and sanitation as part of that assessment.

- A gender perspective needs to be applied, to ensure that increased work-loads are not laid unquestioningly on women, and that the needs of disabled women and men, girls and boys are all considered and addressed.

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Appendix I: Searches

A1.1 Electronic databases searched:

Applied Social Sciences Index and Abstracts ASSIA (CSA)
Article First (OCLC)
British Humanities Index (CSA)
British Library of Development Studies: www.ids.ac.uk/blds
CAB Abstracts
COMPENDEX
EMBASE
Geobase
HealthSTAR (National Library of Medicine)
International Bibliography of Social Sciences (BIDS)
IRCDOC: www.irc.nl/products/documentation/ircdoc/search.html
KIT: www.kit.nl/ibd/extern/opc_main.asp
Medline
OneWorld: www.oneworld.net
POPLINE (National Library of Medicine)
Science Citation Index
Social Science Citation Index (Web of Science)
Social Services Abstracts (CSA)
Sociological Abstracts (CSA)
WHO Library Database (WHOLIS):
www.who.int/library/database/index.en.shtml

A1.2 Web-sites searched:

NGOs/Disability related organisations
AIFO: www.aifo.it/english/homeenglish.htm
BOND (British Overseas NGOs for Development): www.bond.org.uk
Christoffel Blinden Mission: www.cbmi.org
Danish National Council of Disabled People: www.disability.dk
Disability Awareness in Action: www.daa.org.uk
Disability Rights Commission (UK): www.drc-gb.org/drc/default.asp
Disabled Peoples' International. www.dpi.org
Disabled People's International Publications:
www.dpa.org.sg/DPA/publication/dpipub/home.htm
Dutch Coalition on Disability and Development: www.dcdd.nl
Handicap International: www.handicap-international.org/index.html
Handicap International Belge: www.handicap-international.be
Healthlink Worldwide: www.healthlink.org.uk
Healthwrights. www.healthwrights.org

Helpage International: www.helpage.org/
Hesperian Foundation. www.hesperian.org
Impact Foundation: www.impact.org.uk/
Independent Living: www.independentliving.org/
The International Center for the Advancement of CBR:
http://meds.queensu.ca/icacbr/index.html
International Committee of the Red Cross. www.icrc.org
International Disability and Development Consortium: www.iddc.org.uk/
International Special Education Congress 2000: www.isec2000.org.uk
Leonard Cheshire International: www.leonard-cheshire.org/~cheshire/aboutus/intservices/self.html
LEPRA: www.lepra.org.uk
MEND Trust (Mobility Equipment for the Needs of the Disabled)
www.voyager.co.nz/~mend/
Mobility International USA: www.miusa.org/
Motivation: www.motivation.org.uk/contact/
Oxfam: www.oxfam.org.uk
Rehabilitation International. www.rehab-international.org
RNIB: www.rnib.org.uk
Sense International: www.sense.org.uk/international/index.html
Swedish Organizations of Disabled Persons: www.shia.se/englishshia.htm
Sight Savers International: www.sightsavers.org.uk/sitefiles/home/default.htm
World Bank and Disability:
http://wbln0018.worldbank.org/HDNet/HDdocs.nsf/2d5135ecbf351de6852566a9
0069b8b6/066274da1ba9e8da852567e0005215e6?OpenDocument
World Institute on Disability: www.wid.org/

Disability/health-related journals/information networks (14)

Asia Pacific Disability Rehabilitation Journal: www.aifo.it/english/apdrj/apdrj.htm
CBR Forum http://dag.virtualave.net/cbrforum.htm
Center forInternational Rehabilitation Research Information and Exchange:
http://cirrie.buffalo.edu/search
Child Rights Information Network www.crin.org
Disability Information Resources: www.dinf.ne.jp/doc/english/index_e.html
Disability Links. www.geocities.com/Paris/1502/disabilitylinks.html
Disability World web-zine www.disabilityworld.org/
Enablelink: www.enablelink.org/
Enabling Education Network: www.eenet.org.uk
RADAR – the disability network. www.radar.org.uk/index.html
Source: Health and Disability International Information: www.asksource.info/
TALC (Teaching Aids at Low Cost). www.talcuk.org/
Taylor and Francis Journals (Development in Practice, Disability & Society,
Disability & Rehabilitation): www.tandf.co.uk/journals/listings/d.html

UN websites (8):

Food and Agriculture Organisation: www.fao.org/sd/ppdirect/rurald/
World Agricultural Information Centre: www.fao.org/waicent/index_en.asp
International Labour Organisation: www.ilo.org/
United Nations: Persons with Disabilities www.un.org/esa/socdev/enable/
UNESCAP Asia Pacific Decade of Disabled Persons:
www.unescap.org/decade/index.htm
UNESCO: www.unesco.org/education/educprog/sne/index.html
UNICEF: www.unicef.org/
WHO Disability and Rehabilitation: www.who.int/ncd/disability/index.htm
WHO International Classification of Functioning Disability and Health
www3.who.int/icf/icftemplate.cfm

Poverty, Water, Sanitation, Development (8)

Center for Universal Design http://www.design.ncsu.edu/cud/
Focus on Africa Society. Health and Sanitation.
www.africafocus.com/projects.htm
Source- water and sanitation news http://www.wsscc.org/source/
ID21: http://www.id21.org/
Joseph Rowntree Foundation: http://www.jrf.org.uk
ProPoor Newsletter: http://www.propoor.org
UKIID we-site: http://www.ukiid.org/
Wateraid: http://www.wateraid.org.uk/
The Water Page http://www.thewaterpage.com/
WELL http://www.lboro.ac.uk/well/
World Bank and Poverty (PovertyNet): http://www.worldbank.org/poverty/

e-mail discussion lists:

Disability Research
Water-and San-Applied Research
Urban-environmental-health

Electronic newsletters:

Source
Waterpage
Povertynet

Mailing lists:

IDDC members
DPOs
BOND D&DWG members
World Federation of Occupational Therapists network

A1.3 Search terms used

access [1]
activities of daily living
ADL
Africa
Asia
assistive devices
developing countries
disab* (where permitted)
disabilities
disability
disabled
disabled children
disabled persons
drinking water
handicapped
hand pumps
handicapped
handwashing
hygiene
independent living
latrines
personal assistance
rehabilitation
sanitary engineering
sanitation
toilet facilities
toilets
water
water pumps
water supply

[1] 'access' in the context of searches invariably referred to the 'provision' of water and sanitation and not to its 'use'.