Including disabled people in sanitation and hygiene services

The needs of disabled people in developing countries are consistently overlooked when it comes to providing sanitation and hygiene services. This reality has severe and widespread consequences for the health, dignity, education and employment of disabled people and their caregivers. This briefing note explores these issues and suggests how more and better research could influence policy and improve programmes.

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In March 2011, the SHARE consortium, WaterAid and the Leonard Cheshire Disability and Inclusive Development Centre (LCD) brought together 22 researchers and policy-makers with expertise in water, sanitation and hygiene (WASH), equity, inclusion, and disability to share knowledge and experiences, and develop a research programme for disabled access to sanitation and hygiene services.

The group included champions from university departments and organisations with a track record of raising awareness, generating evidence and designing programmes and projects around this neglected issue, as well as policy-makers working for major bilateral and multilateral organisations. Participants brought experiences and updates from Ethiopia, India, Nepal and Madagascar, discussed the results of interventions and the evidence required to support policy change, and called for action. They assessed existing knowledge in order to establish **what we now know**, followed by structured brainstorming to define key questions based on **what kind of information would convince sector stakeholders to act,**

what we feel we need to know and **what we need to do better and more of** in order to both understand and respond to the challenge of providing inclusive sanitation facilities for disabled people.

Capturing the spirit and sentiments of the workshop

For years the sanitation and hygiene needs of disabled people have been treated as low priority, to the detriment of disabled people and the wider community, especially families and caregivers. The barriers that disabled people face when using sanitation facilities have been categorised as environmental (such as steps and narrow doors), institutional (such as a lack of information from authorities and exclusion from consultative procedures) and attitudinal (such as prejudicial attitudes from the community and service providers), but little action has been taken to address these.

A sea-change in disability awareness is now underway, partly due to international agreements such as the UN Convention on the Rights of Persons with Disabilities. Interventions have shown how inclusive design can be inexpensive and benefit pregnant women, older people and the chronically ill as well as disabled people. There is a lack of both quantitative and qualitative evidence, but the emerging findings are clear: the cost of improving access for all is likely to be far outweighed by the benefits.

Box 1
Inclusive development

Inclusive development incorporates **inclusion** (disabled people are recognised as participants in all development activities), **equity** (every person, regardless of their age, gender, disability or ethnicity, benefits from an intervention) and **access** (disabled people do not face barriers in the built environment).

Photo: WaterAid/Layton Thompson

Ramata Coulibaly, member of JIGI Disability Association, by her new latrine in the commune of Tienfala, near to Bamako, Mali

Scale and severity

Disability directly and indirectly affects a significant proportion of the world's population. The World Health Organisation estimates 10% of people worldwide are disabled (690 million people)[1]. One household in four is said to include a person with a disability.

Disabled people and their families tend to be among the poorest of the poor because of factors including:

- Lack of education
- Limited job opportunities
- Reduced family income because of caring for a dependant
- Increased medical expenditure

The lack of inclusive facilities means disabled people often engage in unhygienic and dangerous practices; for example wheelchair users are forced to crawl on the floor of latrines, others defecate in the open to avoid the discrimination associated with using public toilets, and disabled people may also restrict their intake of food and water to avoid needing to go to the toilet.

The policy environment

Improving the lives of disabled people, including their access to sanitation and hygiene services, is not currently a priority within international development policy-making circles. However, the drive to meet targets, such as halving the proportion of the world's population without sanitation – Millennium Development Goal (MDG) seven, should not occur at the expense of equitable progress. It takes relatively small amounts of money to ensure more equitable access, and such actions will improve the health and productivity of hundreds of millions of disabled people. To convince policy-makers to mainstream disability within sanitation and hygiene programmes, we need to present evidence on what is cost-effective, sustainable and works at scale.

This evidence is also needed by disabled people. At the moment information on inclusive sanitation and hygiene options for end users is often inaccessible. This means that disabled people may not know what options are available.

[1] UN (2006) Enable! International Convention on the Rights of Persons with Disabilities. Available at: www.un.org/disabilities

Box 2

Evidence gaps that need to be addressed to influence decision-making

Data: To understand the scale of the problem we need more quantitative data. While data about disability prevalence does exist, it is inconsistent across countries. National censuses are increasingly including disability within their questionnaires, and certain governments, including the Indian Government, are very good at gathering data and have extensive monitoring systems, so there is the potential to enumerate disability in better ways. Ideally data also should be disaggregated by impairment type in order to understand prevalence of specific impairments (blindness, wheelchair use, deafness) and the impact a lack of basic sanitation has on those different impairments. A greater understanding would lead to more appropriate policy development and intervention.

Health: Disabled people are likely to experience increased health risks because of a lack of access to sanitation and hygiene services. They are generally poorer and less likely to be able to pay for services, often require additional WASH services to maintain dignity and hygiene, and are also less likely to receive medical care because of stigma and prejudice. More evidence is needed to understand how a lack of sanitation and hygiene affects the health of disabled people, and to what extent it causes or worsens impairments.

Education: All children need access to sanitation and hygiene in school and it affects their attendance and learning. It is therefore likely that inclusive sanitation and hygiene facilities would help to improve education outcomes for disabled children. More work is needed to understand the extent to which inclusive WASH in schools has improved disabled children's enrolment, attendance and learning outcomes.

Livelihoods: The impact of improved sanitation and hygiene services on carers and the household economy also has to be better understood. Better facilities will reduce exposure to disease and reduce workload, thereby increasing opportunities for income-generating activities for everyone in the household.

Programme effectiveness: Better monitoring and evaluation methodologies are needed to ensure lessons are documented and disseminated widely. Sanitation and hygiene programmes need to be evaluated to understand if they are really accessible for all.

Practice

There are many small scale examples of good practice in making sanitation and hygiene accessible to disabled people in low-income countries. There are also some key lessons emerging from experience.

These include:

- The additional cost of providing inclusive sanitation is only 2 to 3% according to a Water, Engineering and Development Centre (WEDC) case study from Ethiopia.
- Sanitation facilities must really meet the needs and capacities of users or they will not be used. Close attention to detail is required at the design stage.
- Operation and maintenance are also critical; if latrines are not easy to clean then they will not be used. Sanitation interventions need to generate the sustained behaviour change of users alongside inclusive user-friendly design.
- Sanitation projects need to go beyond technical solutions and address attitudinal and institutional barriers to accessible sanitation.
- An explicit recognition of the right to sanitation within national and international laws and conventions can help to prioritise inclusive sanitation and hygiene as a right for all.
- Participation of disabled people in programme design is critical, and Disabled Persons Organisations (DPOs) can help in design. But we need to recognise that DPOs may not always truly represent the diversity of its members. For example, DPOs are often led by urban, educated men so that women's voices and opinions may not be apparent.

We now need to document these lessons and use them to develop programmes that deliver inclusive sanitation and hygiene at scale. Examples of successful policies and practices need to be shared so that good practice can be applied more widely. The costs and benefits of inclusive designs also need to be measured, as do the costs of not considering the needs of disabled people.

Photo: SHARE/ Guy Collender

WaterAid and DFID-funded disabled toilet block, Dhaka, Bangladesh

Key research priorities and suggested actions

Synthesise existing literature on the sanitation and hygiene needs of disabled people, the impact of inadequate facilities in the household and at school, as well as the challenges that disabled people face in relation to sanitation and hygiene.

1 Evaluate interventions designed to benefit disabled people within mainstream sanitation approaches, such as Community-Led Total Sanitation, to document good practice.

2 Undertake in-depth quantitative and qualitative research with disabled people, their families and communities in two countries. This comparative approach would help determine if some challenges are universal. The quantitative element will generate facts and figures relating to the type and extent of the challenges.

3 Develop guidelines regarding baseline questions, indicators and outputs for inclusion within national and international monitoring and evaluation mechanisms.

4 Undertake cost benefit analyses of improving access to sanitation and hygiene services for disabled people, and of not taking action.

5 It is unethical to conduct research to understand a problem and then not attempt to alleviate it. After the initial research the team will design interventions to respond to the research findings, and then use similar methodology to assess the impact of intervention.

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Listen to the workshop podcast

http://soasradio.org/content/toilets-all-why-and-how-facilities-must-be-improved-disabled-worldwide

Further resources on disability and WASH

www.wateraid.org/uk/what_we_do/how_we_work/equity_and_inclusion/8319.asp

http://asksource.ids.ac.uk/cf/keylists/keylist2.cfm?topic=dis&search=QL_WASH10

www.wateraid.org

www.ucl.ac.uk/lc-ccr

www.shareresearch.org

http://wedc.lboro.ac.uk

www.lshtm.ac.uk

www.wsscc.org

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