Leonard Cheshire Disability and Inclusive Development Centre, University College London

Cross-cutting Disability Research Programme

Background Paper: 04

Undoing inequity: inclusive water, sanitation and hygiene programmes that deliver for all: Uganda and Zambia

Key Findings

- Disabled, chronically ill and older adults in Zambia and Uganda face common physical, attitudinal and intuitional barriers to accessing water, sanitation and hygiene (WASH).
- A significant percentage help fetch water but face considerable difficulties because of distance, inaccessible water points and difficulties in carrying water.
- Current storage arrangements for water in households, latrine structures and bathing arrangements are inaccessible for many. Simple adaptations could improve accessibility, allowing greater independence and choice for vulnerable persons and lessening the amount of time carers spend on assisting with routine activities.
- Many who need help getting water, going to the latrine or bathing routinely limit such activities so they do not overtax caregivers. (I.e.: go thirsty, wait to eat until later in the day so they do not have to use the latrine before someone is home to help them, bathe less frequently than other household members). Such actions have serious health implications as well as concerns regarding rights and dignity.
- In both Uganda and Zambia, three quarters of the carers reported providing assistance 'many times' or 'always' during the day. 41% plan daily schedules around providing care and most of these activities are WASH related.
- The majority of vulnerable individuals interviewed were interested in minor, low cost adaptations to increase accessibility of WASH facilities.
- Heads of households and vulnerable members expressed interest in adaptations to improve accessibility, but many do not know where to start. Information and technical support is needed.

Introduction

This briefing note reports baseline findings from a research project to understand the barriers disabled, older people and people living with a chronic illness face when accessing WASH in Zambia and Uganda. Three leading sector organisations in water, sanitation and hygiene and disability – Leonard Cheshire Disability, WaterAid, and the Water, Engineering and Development Centre (WEDC) – are collaborating on this project, and worked in partnership with the Appropriate Technology Centre (ATC) in Uganda and the Institute of Economic and Social Research (INESOR) in Zambia to collect baseline data in the two countries.

Background

Millennium Development Goal 7 calls for reduction by half of people without sustainable access to safe drinking water and basic sanitation by 2015. (1)

Globally, 768 million people live without access to safe water and 2.5 billion people lack access to improved sanitation. (2)

While access to WASH is an issue for a significant proportion of the world's population, a growing body of data indicates that certain groups of people face disproportionate amounts of poverty, stigma and social marginalisation. These include:

- 15% of people worldwide (1 billion people) who live with a disability.(3)
- 11% of the world's population (740 million people) who are aged 60 and over. This number is set to rise to 1billion by the end of the decade.(4)
- 34 million people living with HIV and others living with a chronic illness.(5)

Despite the numbers involved, there is little knowledge about these marginalised populations' access to water, toilets or bathing facilities, and there is limited evidence-based data about barriers faced when accessing WASH services in low- and middle-income countries. (6) These barriers can be categorised into three groups (7):

1. **Physical barriers:** (a) environmental – e.g. distance to water source, difficult paths to latrines or (b) man-made– e.g. toilets that are too small for a wheelchair user to enter and turn inside

2. **Attitudinal barriers:** e.g. lack of information on the cause of a disability or illness leading to negative beliefs, stigma or discrimination

3. **Institutional barriers:** e.g. vulnerable people are often excluded from decision making processes which affect them; information on accessible WASH is rarely accessible for everyone

Overview of the research

The aim of this study is to understand the barriers faced by: persons with disability, chronically ill and frail older people in accessing and using standard WASH facilities. An inclusive WASH approach to address the barriers faced will be

developed and tested in order to improve access to WASH for all.

The key questions are:

- What are the problems and opportunities currently experienced by people who are marginalised and their households in accessing and using WASH facilities?
- What solutions and approaches improve access to WASH for all within a community WASH intervention?
- What are the benefits of improved access to WASH for vulnerable individuals and their families?
- What are the additional programme costs to undertake an inclusive WASH approach?
- What tools can be used in future research and in the programme cycle to support WASH programming that reduces intra-household disadvantage, and to measure the impact of an inclusive approach to WASH?

Study area

Research was undertaken in 13 sub-counties in Amuria and Katakwi, Uganda, and in Mwamza West Ward, Monze, Zambia, where WaterAid's partners are already implementing water and sanitation programmes.

Study design

The data reported in this briefing note was collected in a pre-intervention baseline study (Phase 1) gathering quantitative and qualitative data in both countries. This precedes an inclusive WASH intervention by WaterAid and partners, Development Aid from People to People (DAPP) in Zambia, and Wera Development Association (WEDA) and the Church of Uganda Teso Diocese's Planning and Development Office (CoU-TEDDO) in Uganda (Phase II). A post-intervention study will be completed to assess the impact and benefits of the intervention for the target group (Phase III).

Methodology

Data was collected using a mixed methods approach (qualitative: interviews, focus groups, structured observations; and quantitative: linked household head/ household member survey who is disabled, chronically ill or older adult).

Vulnerable households were identified through village-level government lists of households with disabled, older and/or chronically ill members. Matched data was collected from household in the same community with no vulnerable individuals in the household.

In Uganda, of the 314 household were surveyed (37% in Amuria, 63% in Katakwi). 131 households (42%) had one or more member who was disabled, chronically ill or an older adult as identified by questions adapted from the UN Statistical Commission's Washington Group on Disability Statistics. In Zambia, out of 244 households surveyed were surveyed 128 (52%) had one or more member disabled, chronically ill or an older adult.

Structured observation of WASH facilities at household, school and community level was carried out using observational checklists.

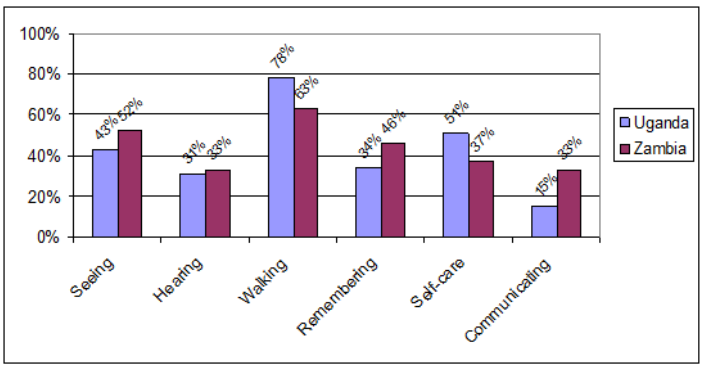
Interviews with senior ministry officials and experts from NGOs working in the WASH sector as well as representatives from disabled people's organizations were undertake to supplement the survey, interview and observational data.

Findings

The areas in which this project is being carried out are both rural districts, largely agricultural in nature.

Those household members who reported being disabled, chronically ill or older experienced a range of impairments. In both countries, physical disability was the most commonly reported type of disability, followed by issues of self-care and sensory disabilities'.[1]

Figure 1 Reported Impairment Type by Country



[1] Respondents could give more than one answer which is why these numbers add up to more than 100.

Access to water

Almost everyone in the household uses the same water source (Uganda 98%; Zambia 95%) from boreholes, tube wells and unprotected sources such as shallow wells.

A significant percentage of all vulnerable individuals help fetch water (Uganda 32%; Zambia 48%). These individuals reported considerable difficulties in doing so (Uganda 73%; Zambia 70%), including weakness, impairment or sickness (61%), the heavy weight of containers (33%) and the distance to the water point (21%).

In both countries, a series of physical barriers were identified:

- Water sources far from the homestead
- Heavy hand pump handles on boreholes, and handles that some cannot reach
- Time spent waiting in line for water, and the fact that they are often not allowed to go before others, even it is difficult for them to stand for long periods.
- Difficulty in carrying as much water as needed back to house because of the weight of the container
- In addition, attitudinal barriers were encountered. In Uganda, 19% reported they were told not to touch water due to their condition (disability, illness or weakness). The rate was lower in Zambia (3%) but the attitude was not unknown. Some tap owners will turn people with vulnerabilities away even

when they can pay. The reasons given by the respondents were that some believed vulnerable individuals were dirty or could contaminate the water source. A fear among family members that the vulnerable individual might slip and fall into the water was also reported by several respondents and this was a particular concern for persons with epilepsy.

- Examples of institutional barriers include the annual pump fees which are difficult for some to pay, and allowances or exceptions are not always made for vulnerable people.

Access to Drinking Water in Household

- Access to stored water at home proved another significant area of concern. In Zambia, all respondents reported everyone in the household had access to enough drinking water, but in Uganda, only 84% of respondents reported having enough drinking water throughout the year.

- However in both countries many vulnerable individuals who were interviewed reported that within their households, they must wait for others to help them get water as it is stored in a manner that restricts these individuals' ability to easily get water for themselves. It is stored in heavy containers on high shelves or in places where it is difficult for them to reach, lift or manoeuver.

- The result is that during the day, many vulnerable individuals do not get enough drinking water. In Uganda, 29% said that they cannot get the drinking water container by themselves due to physical limitations and 35% reported that vulnerable individuals use less water. In Zambia 22% of all vulnerable individuals report having to wait for help from someone in order to access drinking water.

- In both countries, vulnerable individuals interviewed noted that they hesitate to ask for water as frequently as they want either because there is no one to help them or they do not want to over burden household members by asking for help too frequently.

- Few adaptations were observed or reported in accessing water (e.g. use of lighter containers, containers that could be pulled, frames that could allow water to be more easily tipped out of containers, storage of household water on lower shelves or tables). Lack of knowledge about possible adaptations was an issue.

Access to sanitation

- In Uganda 24% and in Zambia 16% of vulnerable people do not use the same latrine as the rest of the household.

- Physical barriers were common: slippery paths or distance from household, steps, narrow doorways, lack of adequate lighting and limited room within the latrine which would necessitate a person who needs a wheelchair or crutches having to crawl across a dirty floor. Vulnerable respondents also reported being discouraged for using the same latrine

by some family members who said they are 'unclean'.

- Vulnerable members who do not have access to the same latrine as the rest of the household generally use nearby fields or bush, or they use paper or plastic on spread on the floor or a bedpan or bucket. Such sites have no water or other materials available to clean themselves. Issues of dignity, safety and self-esteem were all raised by respondents who struggled to use the same latrine as other members of their household or who were unable to do so.

- A number of those interviewed (Uganda, 15%; Zambia 16%) report needing some help to reach the latrine, get on/off, or balance while using the latrine. Care is generally provided by women but other household members (including men, children and grandchildren) are routinely called upon.

- In Uganda 40% of those who need help report they have to wait, 'very often' or 'always' for someone to help them use the latrine**,** while in Zambia, 28.5% respondents have to wait 'sometimes' and 43% (n=9) reported they 'always' need to wait.

- Individuals who need help with using the latrine often adapt their behaviour to place less strain on household members. In qualitative interviews, some report asking to go to the latrine less often than they actually need. Others refrained from eating or drinking as much as they would like so that they will use the latrine less often. Several reported waiting until late in the day to eat, so they will not use the latrine until there is someone at home to help them. This has serious implications in populations where eating enough nutritious food is already a concern for many (for example, for children with cerebral palsy, people living with AIDS or frail older adults).

- A number reported soiling themselves while waiting for assistance, with loss of dignity to themselves and additional work for carers.

Hygiene

- Vulnerable adults who needed assistance in carrying water or in bathing, bathed less frequently because they did not want to overtax caregivers.

- In both countries most household heads bathed daily (Uganda 85%; Zambia 86%); but among the vulnerable groups, in Uganda only 67% and in Zambia, only 63% bathe daily. In both countries, one in four vulnerable individuals (Uganda 26%; Zambia 25%) report being unable to bathe on a regular basis.

- Many vulnerable informants did not want to place too much burden on those fetching water or assisting them in bathing, and a number said they were ashamed because they were unclean or smelled. There are health implications here as well. People with

physical disabilities who sit or lie for long periods of time, are at risk of getting pressure sores, people living with HIV have sores and abrasions. If these sores or abrasions are not kept clean, individuals are at risk of infections that can be life threatening.

Carers

- A significant proportion of all carers (Uganda 77%; Zambia 73%) reported that they 'many times' or 'always' took time away from other income producing activities to assist a relative with WASH related activities. In Zambia, a high percentage - 41% said they plan their daily schedule around the needs of the vulnerable household member.

- Most of the key activities for which carers stayed at home were WASH related – getting drinking water and helping individuals reach and use the latrine, as well as helping the individual bathe themselves, and washing clothes for those who cannot wash their own.

- In many cases, the inability of vulnerable persons to undertake these activities for themselves are due to physical barriers that could be adapted to be accessible. Barriers include water stored in containers that are too heavy to manage, latrines that lack doors that can be easily closed or grab bars that allow an individual to steady him/herself.

Lack of WASH Facilities in Public Spaces

- Finally, lack of accessible latrine facilities in public places (markets, churches, schools) limits the options people have to find work outside the home.

- In Uganda, 39 % and in Zambia, 13% of vulnerable respondents reported having trouble finding an accessible latrine in the community.

- In interviews and focus groups, several disabled persons reported that while they use public facilities, they are often teased and jeered at by other community members.

Innovation of WASH facilities

- We found that many households with vulnerable members had already tried to make some adaptation to improve access to latrines (Uganda 25%; Zambia 25%). The most common types of adaptations were improving paths latrines and moving latrines nearer the house.

- In those households where some innovation had been tried, half of the vulnerable individuals were not consulted before adaptations were implemented.

- There was interest in adapting latrine facilities, but many people stated they had never thought about it or did not know where to start. One in four respondents (both household heads and disabled, older and chronically ill

family members) said they thought that 'nothing could be done.'

- Interestingly, when vulnerable members were asked about the type of changes that would potentially help them better meet their toileting needs, most referred to simple additions (46%).

- While discussion of changes to toilets was the focus of attention, less attention was directed towards potential changes in water carrying, storage or bathing despite the fact that these facilities can be made accessible.

- This reflects the lack of knowledge about the possibilities available. There was the suggestion (and request) from household heads and vulnerable individuals, that pictures, designs, photos and information on how simple adaptations to latrines could be made would be useful.

Policy Implications

The concept of 'equity and inclusion' in access to water, sanitation and hygiene is built upon the idea of a human rights based approach, and supported by a number of key national pieces of legislation and active civil society:

The governments of both Uganda and Zambia are signatories to the UN Convention on the Rights of Persons with Disabilities.

Both Uganda and Zambia have prominent legislation at the national level regarding inclusion of persons with disabilities, protection of older adults, support inclusion and rights of people living with AIDS and other chronic illnesses.

Both Uganda and Zambia have prominent, highly regarded disability rights organisations (DPOs) that have been models for advocacy in many countries around the world.

Uganda has the most advanced Sector Wide Approaches in the WASH sector in Africa.

However, a key challenge is translating policy into practice at the district level and below, and linking these to efforts to improve equity and inclusion in the WASH sector. For example, in Zambia a permit from the government to dig bore holes is required, but there is currently no provision in this process to ensure that any new bore hole dug is accessible for vulnerable individuals where possible. Inclusion of this provision in order for contractors, NGOs or other groups to be given permission to dig a new bore hole would be an effective institutional intervention.

Next steps

This study has found there is a need for documentation and dissemination of evidence at household, community and government levels.

There is also a need for increased collaboration and dialogue among stakeholders on the provision of inclusive WASH services – both within WASH and between WASH and the practitioners and advocates working on behalf of persons with disabilities, older adults and people living with chronic illness, such as people living with AIDS.

In the second phase of this study, WaterAid will lead with partners to test an inclusive WASH approach in the districts surveyed here. The approach will be monitored throughout the intervention in order to identify strengths and weaknesses of the inclusive WASH approach.

References

1. United Nations. Millennium Development Goals. http://www.un.org/millenniumgoals/

2. WHO/UNICEF Joint Monitoring Programme (JMP) report 2013

3. WHO (2011) World report on Disability (2011) http://www.who.int/disabilities/world_report/2011/en/index.html

4. OHCHR (2011) HUMAN RIGHTS OF OLDER PERSONS: Summary of the Report of the Secretary-General to the General Assembly,

5. UN AIDS. 2013. Data and Analysis 2011 http://www.unaids.org/en/dataanalysis/

6. Groce N, Bailey N, Lang R, Trani JF, Kett M. (2011) Water and sanitation issues for persons with disabilities in low- and middle-income countries: a literature review and discussion of implications for global health and international development. Journal of Water and Health, 9:4:617–627

7. Jones H, Fisher and Reed (2012) Water and sanitation for all in low-income countries, Municipal Engineer, 165(3), 167-174.

About the Cross-Cutting Disability Research Programme (CCDRP)

The CCDRP is a three year research programme on disability and development funded by the UK Department for International Development (DFID). Based at the Leonard Cheshire Disability and Inclusive Development Centre, Department of Epidemiology, University College London (UCL), the goal of this project has been to generate new understanding of the links between disability and global poverty in mainstream development and health areas where little attention has previously been directed towards persons with disability: maternal and child health, water and sanitation, and agriculture, as well as to better understand issues of access to mental health services in peri-urban communities. Research has been concentrated in five countries: Kenya, Zambia, Uganda, India and Nepal. The programme is also supporting a number of other stakeholders, including disabled people's organisations and local academic institutions to mainstream disability and development research.

The overarching aim of this research has been to contribute to an increase in the effective and sustained social and economic inclusion of disabled people in international development and global health initiatives through the generation of evidence-based research, as well as the capacity building of a range of partners to strengthen mutual understanding around disability inclusion.

For more information about this research, contact ccdrp@ucl.ac.uk

This research has been funded by UKAID from the UK Government. However the views expressed do not necessarily reflect the UK Government's official policies.