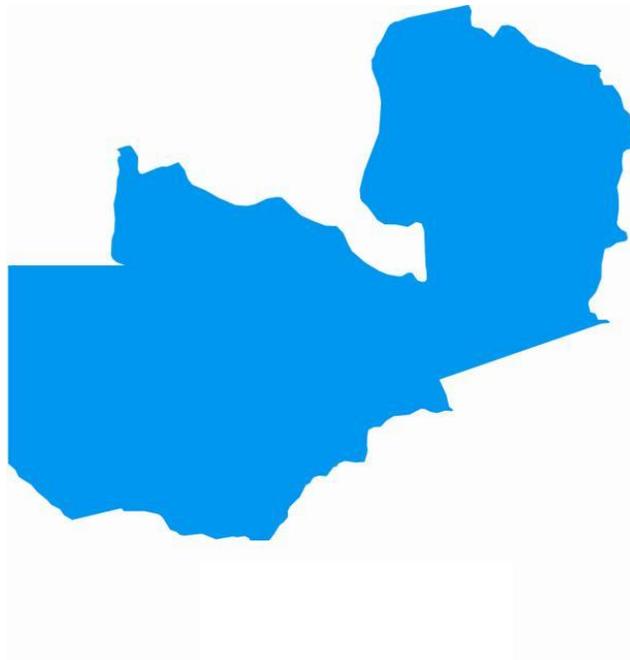


# Undoing Inequity: inclusive water, sanitation and hygiene programmes that deliver for all in Zambia.

Baseline survey findings.



Groce N, Tramontano C, Wilbur J, Jones H, Cavill S, Gosling L, Mamo J (2014). Undoing Inequity: inclusive water, sanitation and hygiene programmes that deliver for all in Zambia. Baseline survey findings. LCD, WaterAid, WEDC.



## Executive summary

### Background

This study, undertaken in the Mwanza West Ward in Monze, Zambia, by Leonard Cheshire Disability Inclusive Development Centre (LCDIDC), WaterAid and the Water Engineering Development Centre (WEDC) at Loughborough University, working in collaboration with WaterAid Zambia and the University of Zambia's Institute of Economic and Social Research (INESOR), sought to help build an evidence base on common environmental, attitudinal and institutional barriers to accessing WASH faced by 'vulnerable individuals'. For the purposes of this study, 'vulnerable individuals' is a group that includes people with disabilities, people with chronic illness and older adults – i.e. people who consistently have difficulty accessing WASH services. Specifically we sought to understand what barriers exist to the equitable use of WASH services, and how experiences of vulnerable individuals might differ from those of non-vulnerable individuals in the same households and communities.

Using a 'mixed methods' approach – including interviews, focus groups, surveys and structured observational tools – information was collected from vulnerable individuals and heads of their households, and from members of their communities, community leaders, teachers, officials within national ministries and local government, and from experts and advocates in civil society working both in the WASH sector and in groups representing people with disabilities, those who live with chronic illness and older adults.

### Key findings

People with disabilities or chronic illness and older adults in Zambia face common environmental, attitudinal and institutional barriers to accessing WASH. The research yielded several key findings that are relevant WASH practitioners.

#### Access to water services

45% of all vulnerable individuals help fetch all or some of the water needed by their household. However, 55% of those who do fetch water report facing considerable difficulties because of distance, inaccessible waterpoints and difficulty in carrying enough water to meet their daily needs. This shows that, although they are considered 'vulnerable' and in need of assistance, they must still be considered as primary users of WASH services.

The findings also show that the families of vulnerable individuals consider their physical limitations to be the main barriers to WASH access – i.e. the 'problem' lies in the individual. Few of those interviewed identified environmental, attitudinal or institutional barriers that might prevent vulnerable individuals from being able to

collect water themselves. No-one recognised that these barriers could be modified or changed.

Those members of households who are unable to fetch water for themselves rely on other members of their households and neighbours. However, whether fetching water themselves, or relying on others, many vulnerable individuals limit the amount of water they use, by eating and drinking less throughout the day and bathing less frequently in order to not overtax caregivers. Limiting water and food can have serious health implications, and raise concerns about rights and dignity.

### Caregivers

In Zambia 73% of caregivers reported providing assistance ‘many times’ or ‘always’ during the day, forgoing other income-producing activities and social interactions. A substantial proportion of this assistance is WASH-related. Additionally, since most caregivers are women, the subject also becomes a gender issue.

### Adaptations to WASH facilities

Although inclusive WASH is intended for all members of the community, interest in making facilities accessible at the household level is understandably primarily of interest to those households with a vulnerable member.

36% of households with vulnerable individuals surveyed had already tried some form of adaptation. However, lack of information or options made many of these adaptations ineffective. The lack of knowledge about where to begin and what changes to make were identified as the key barriers to making improvements. This indicates the existing demand for low-cost, low-tech WASH adaptations.

Both household heads and vulnerable individuals expressed interest in adaptations to improve the accessibility of WASH services, generally reporting that minor, low-cost improvements would be of particular interest and would benefit all family members.

### Lack of WASH Services in public spaces

Lack of accessible WASH services in public spaces such as markets, churches and mosques, schools and health clinics are substantial barriers to full participation in the community.

### WASH services in schools

It is important to note that there were relatively few students with physical disabilities recorded. This might have a bearing on the lack of accessibility issues raised, which would be less of a reflection of improvements and more likely to be due to the small number of students with physical disabilities. This reflects additional environmental barriers outside the school, such as lack of adequate transportation.

Teachers indicated that, in all schools, children use the same water sources and toilets, irrespective of particular needs; none of the participating schools had a

separate ‘disabled’ toilet. Additionally, although teachers did not feel like there were major environmental barriers to people with disabilities accessing the toilets, the observational study indicated otherwise.

The large ratio of number of students to number of toilets raises a major problem for all students. As students run to the toilets during break time, children with disabilities, who might be slower in reaching the toilets, are placed at a competitive disadvantage, increasing the chances of soiling themselves.

### Attitudes towards vulnerable people

Although several people reported that progress has been made in changing attitudes towards vulnerable individuals, various members of the community reported regularly encountering traditional negative beliefs. During focus groups, it became evident that some members believe that disability is contagious, or that any interaction with people with disabilities would cause a mother to give birth to a disabled child.

### Institutional support

Many community leaders, government administrators and senior government officials are already working on WASH issues. Several of these officials are also involved in efforts to improve the lives of vulnerable members of their communities. Most have not, however, linked their work with vulnerable populations to their work on WASH.

There has been little interaction at local, district or national levels between the WASH sector and government agencies, non-governmental organisations, experts and advocates for vulnerable populations. This is an institutional barrier and a lost opportunity.

The research also showed that lack of accessible latrines meant that, in areas where development plans were moving forward, the participation of an effective representative cohort from the disability community was missing. This is simply due to vulnerable individuals not being able to access sanitation services when needed, increasing the likelihood that they might avoid attending meetings.

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## Glossary and abbreviations

### Acronyms and abbreviations

AIDS	Acquired Immune Deficiency Syndrome
CCDRP	Cross Cutting Disability Research Programme
CLTS	Community Led Total Sanitation
CRPD	Convention on the Rights of Persons with Disability
DFID	Department for International Development
DPOs	Disabled Persons Organisation
DPA	Disabled Persons Association
FGDs	Focus Group Discussions
INESOR	Institute for Social and Economic Research
LCD	Leonard Cheshire Disability
LCDIDC	Leonard Cheshire Disability and Inclusive Development Centre
NGOs	Non-Governmental Organisations
SDG	Sustainable Development Goal
SHARE	Sanitation and Hygiene Applied Research for Equity
SPSS	Statistical Package for the Social Sciences
MDG	Millennium Development Goal
UCL	University College London
UN	United Nations
WASH	Water, Sanitation and Hygiene
WAZ	WaterAid Zambia
WEDC	Water, Engineering and Development Centre
ZAFOD	Zambian Association of the Disabled

## Glossary

Term/ technology	Explanation
Access	People are described as having access to a water or sanitation service if they can use a functioning facility within a reasonable distance of their home, and without exclusion on the grounds of race, tribe, religion, disability, age, illness, gender or other cause.
Chronic illness	Defined as living with a serious health condition for one year or longer. Examples include cancer, HIV or AIDs, chronic respiratory diseases and diabetes.
CLTS	Community-led Total Sanitation (CLTS) is an approach to the promotion of sanitation which brings about a collective community decision to reject open defecation. Communities strive to achieve Open Defecation Free (ODF) status. CLTS in its ‘pure’ form does not recommend or subsidise specific sanitation technologies
Disability	The World Health Organization, acknowledging the complex interactions between physiological, environmental, and socio-cultural issues, states that a person is considered disabled through an interaction between that person's health condition, the surrounding contextual factors (e.g. socio-cultural attitudes, architectural barriers, legal and social structures) and personal factors <sup>1</sup> (e.g. age, gender, educational and social background, individual temperament) (WHO, ICF 2002).
PHAST	Participatory Hygiene and Sanitation Transformation
Coverage	The proportion or percentage of the population who enjoy an ‘improved’ water or sanitation service, as defined by the WHO/UNICEF Joint Monitoring Programme (JMP).
Hardware	The ‘hard’ or physical infrastructure (e.g. pumps, pipes, taps and toilets) that makes water, sanitation and hygiene services possible.
Hygiene	Personal and household practices such as handwashing, bathing and management of stored water in the home, all aimed at preserving cleanliness and health.
Menstrual Hygiene Management	Women and adolescent girls use a clean material to absorb or collect menstrual blood, with this material changed in privacy as often as necessary for the duration of the menstrual period. MHM includes soap and water for washing the body as necessary, and having access to facilities to dispose of used menstrual

	management materials.
Older adult	60 years old and above
Impairment	A long-term limitation of a person's physical, mental or sensory <sup>2</sup> function.
Infrastructure	The basic physical and organisational structures needed for a society or enterprise to function. In this paper we refer to the 'hard' or physical infrastructure (e.g. pumps, pipes, taps and toilets) and the 'soft' infrastructure (especially community-level management structures).
Sanitation	In the narrow sense, the safe disposal or re-use of human excreta. In the broad sense, excreta management together with solid waste and storm water management.
Sector	The arena in which the collective endeavours of governments, donors, the private sector and civil society collaborate to improve water, sanitation and hygiene services.
Software	Activities which mobilise households and communities and establish the 'soft' infrastructure (especially community-level management structures) which is necessary for the functioning of water, sanitation and hygiene services.
Sustainability	Sustainability is about whether or not WASH services and good hygiene practices continue to work and deliver benefits over time. No time limit is set on those continued services, behaviour changes and outcomes. In other words, sustainability is about permanent beneficial change in WASH services and hygiene practices.
Tippy tap	A low-cost water dispenser for handwashing, usually made from a plastic container.
WASH	Water, sanitation and hygiene.
WASH sector	The arena in which the collective endeavours of governments, donors, the private sector and civil society collaborate to improve water and sanitation services.
Water technologies	Boreholes and rainwater-harvesting.
Borehole/ tubewell	A cylindrical hole (usually deeper than 20m and less than 0.5m in diameter) constructed to allow groundwater to be abstracted from an aquifer.
Rehabilitated	Rehabilitation is the action taken to repair a borehole that has

borehole	declined in productivity or failed through lack of monitoring and maintenance of the pump or well structure.
Installed borehole	In the narrow sense in relation to this study, this refers to a borehole.
Inclusive design	Infrastructure design that takes into account the needs of people who have difficulties using standard infrastructure because of disability, age, chronic illness or other factors.
Unprotected source	A source likely to provide water that is unsafe for drinking, e.g. an unprotected spring or hand-dug well, a street vendor or tanker.
Surface water	Term used to describe rainwater that runs over land (i.e. does not infiltrate the ground). Surface water, unlike groundwater, is generally not safe for consumption because it accumulates pathogens, metals, nutrients and chemicals as it flows across contaminated surfaces.
Handpump	Devices that raise underground water to the surface and are operated by hand. They are available in various types (e.g. Afridev, India, Nira).
Tapstand	A distribution system of small-diameter MPDE pipes, laid in trenches, feeds and tapstands. A tapstand is a concrete post supporting a 15mm mild steel riser pipe from the pipeline to a bibcock.
Water-borne toilet	Household or public toilet that disposes of human liquid and solid waste, by using water to flush it through a drainpipe to another location for disposal (Ministry of Health Uganda).
Ventilated Improved Pit Latrine (VIP)	This is a dry pit latrine ventilated by a pipe that extends above the latrine roof. The open end of the vent pipe is covered with gauze mesh or fly-proof netting and the inside of the superstructure is kept dark.
Traditional Pit Latrine with concrete sanplat	The sanplat is the cheapest and most basic pit latrine. It is a small concrete platform (usually 60x60cm or smaller), laid on top of logs or other supporting material traditionally used to cover the pit. The purpose of the sanplat is to provide a sanitary (san) platform (plat) which can be easily cleaned to limit the presence of helminths such as hookworm.
Pit latrine with slab	This is a dry pit latrine whereby the pit is fully covered by a slab or platform that is fitted either with a squatting hole or seat. The platform is solid and can be made of any type of material (concrete, logs with earth or mud, cement, etc.) as long as it adequately

	covers the pit without exposing the pit content other than through the squatting hole or seat
Traditional Pit Latrine without slab	This uses a hole in the ground for excreta collection and does not have a squatting slab, platform or seat. An open pit is a rudimentary hole.
Open defecation	Defecation in fields, forests, bushes, bodies of water or other open spaces.
Open Defecation Free	Open Defecation Free – an aspiration in most total sanitation approaches.

## 1 Introduction

MDG 7 calls for the number of people without sustainable access to safe drinking water and basic sanitation to be halved by 2015.<sup>1</sup> Globally, 768 million people live without access to safe water and 2.5 billion people lack access to adequate sanitation.<sup>2</sup> MDG 7 underscores the fact that access to safe water and basic sanitation is a key component of broader international development and global health. It is widely acknowledged that the lack of safe water and adequate sanitation severely restricts people's ability to live with dignity and remain healthy, productive and able, in order for them to pursue an education and employment and participate in the economic, social and cultural life of their communities.<sup>3</sup>

Although access to WASH is a problem for a large proportion of the world's population, a growing body of data indicates that particular groups of people face disproportionate levels of poverty, stigma and social marginalisation. These include:

- People with disabilities – 15% of the global population (1 billion people)<sup>4</sup>
- People aged 60 and over – 11% of the world's population (740 million people), set to rise to 1 billion by the end of the decade<sup>5</sup>
- 35 million adults and children living with HIV<sup>6</sup>

Marginalisation of these large populations is of particular concern in light of the Right to Water and Sanitation guaranteed by the UN High Commission on Human Rights, which states that the water supply for everyone must be “sufficient and continuous, within safe reach and physically accessible to all sections of the population,” with the needs of “persons with disabilities, women, children and older people taken into account”.

### Box 1: The Right to Water and Sanitation

The Right to Water and Sanitation<sup>7</sup> states that:

- 1) The water supply for each person must be sufficient and continuous to cover personal and domestic uses, which comprise water for drinking, washing clothes, food preparation and personal and household hygiene.
- 2) Water for personal and domestic uses must be safe and acceptable. It must be free from elements that constitute a threat to a person's health. Water must also be of an acceptable colour, odour and taste to ensure that individuals will not resort to polluted alternatives that may look more attractive.
- 3) Water and sanitation facilities must be physically accessible and within safe reach for all sections of the population, taking into account the needs of particular groups, including persons with disabilities, women, children and older people.
- 4) Water services must be affordable to all. No individual or group should be denied access to safe drinking water because they cannot afford to pay.

The Right to Water and Sanitation<sup>7</sup> is echoed in the UN CRPD, now ratified by over 140 countries, which in Article 28 (Adequate standard of living and social protection) specifically calls for “equal access by persons with disabilities to clean water services”.<sup>8</sup>

Despite strong statements from the global community, relatively little attention has been paid to the needs of vulnerable groups who face common barriers to obtaining safe water and adequate sanitation.

Despite the numbers involved, there is little knowledge about these vulnerable populations' access to safe water, sanitation or hygiene (bathing, handwashing, laundry facilities), and there is little evidence about the barriers faced in accessing WASH services, especially in low-income and middle-income countries.<sup>9</sup> However, it is clear these groups encounter common barriers to WASH services because of physical limitations, poverty and social marginalisation. Such barriers can be grouped into three categories: environmental, attitudinal and institutional (see Box 2).

### Box 2: Barrier to access

1. **Environmental barriers:** including barriers in the natural environment, such as distance to water sources and difficult paths to latrines; barriers in the built infrastructure; and artificial barriers such as toilets too small for a wheelchair user to enter and turn inside, or wells with sides too high or pump handles too heavy for individuals who have difficulty moving or lifting.
2. **Attitudinal barriers:** lack of information on the cause of a disability or illness or the abilities of people with disabilities to contribute to their households and communities, which leads to negative beliefs, stigma or discrimination.
3. **Institutional barriers:** Vulnerable people are often marginalised and excluded from decision-making processes which affect them; information on accessible WASH is rarely accessible to everyone.

## 1.1 Research aim and questions

To begin to address this lack of data, a collaborative research project was developed between LCDIDC at UCL, WaterAid and WEDC at Loughborough University, in conjunction with colleagues at INESOR at the University of Zambia and WaterAid Zambia.

The aim of the study is to understand the common barriers faced by vulnerable individuals in accessing and using standard WASH services. For the purposes of this study, we include in this 'vulnerable' group, people with disabilities, people with chronic illness and older adults – groups that are consistently found to have difficulty accessing WASH services (see Box 3). Specifically we sought to understand what barriers exist to the equitable use of WASH services, and how experiences of vulnerable individuals might differ from those of non-vulnerable individuals in the same households and communities.

### Box 3: Defining and identifying 'vulnerability'.

For the purposes of this study, the definition of disability from the UN CRPD was used:

Disability is an 'evolving concept' and that a person is disabled as a consequence of the interaction between the individual who has a physical, sensory (deafness, blindness), intellectual or mental health impairment, and the surrounding environment in which he or she lives. Type of disability was identified using questions adapted from the UN Statistical Commission's Washington Group on Disability Statistics 'Short Set' of questions (UN Statistics Division, 2013).

People with chronic illness were defined as people living with a serious health condition for one year or longer, and older adults were defined as individuals aged 60 and older.

This study uses 'vulnerable' to collectively refer to people with disabilities, older people and chronically ill people. It is recognised that not all of these people are vulnerable –the situation dictates whether individuals are vulnerable. In this report, 'vulnerable' relates to individuals or groups who are vulnerable to mental or physical harm due to a disadvantaged social status.

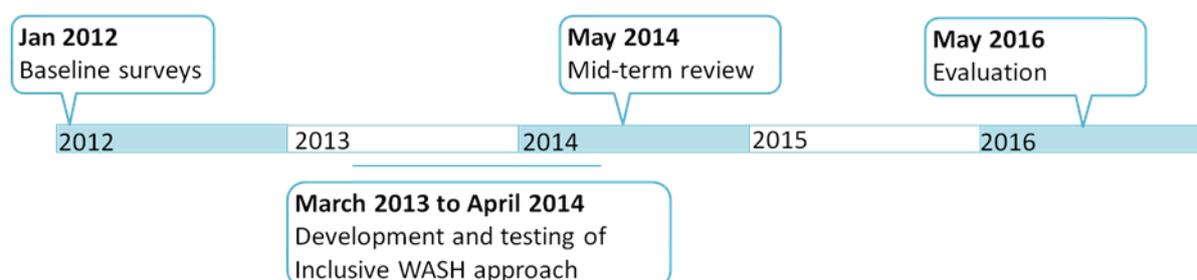
The aim will be achieved by answering the following research questions:

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

The research is a straightforward action-research design. Baseline data were collected to answer the first research question. On the basis of analysis of the baseline data, an inclusive and accessible WASH intervention will be designed and implemented. A mid-term review and evaluation will then be conducted to answer the last three research questions.

A progress marker is that other organisations and academic institutions will use the methods to carry out further research and build on the questions in future research.

## 1.2 Research timings

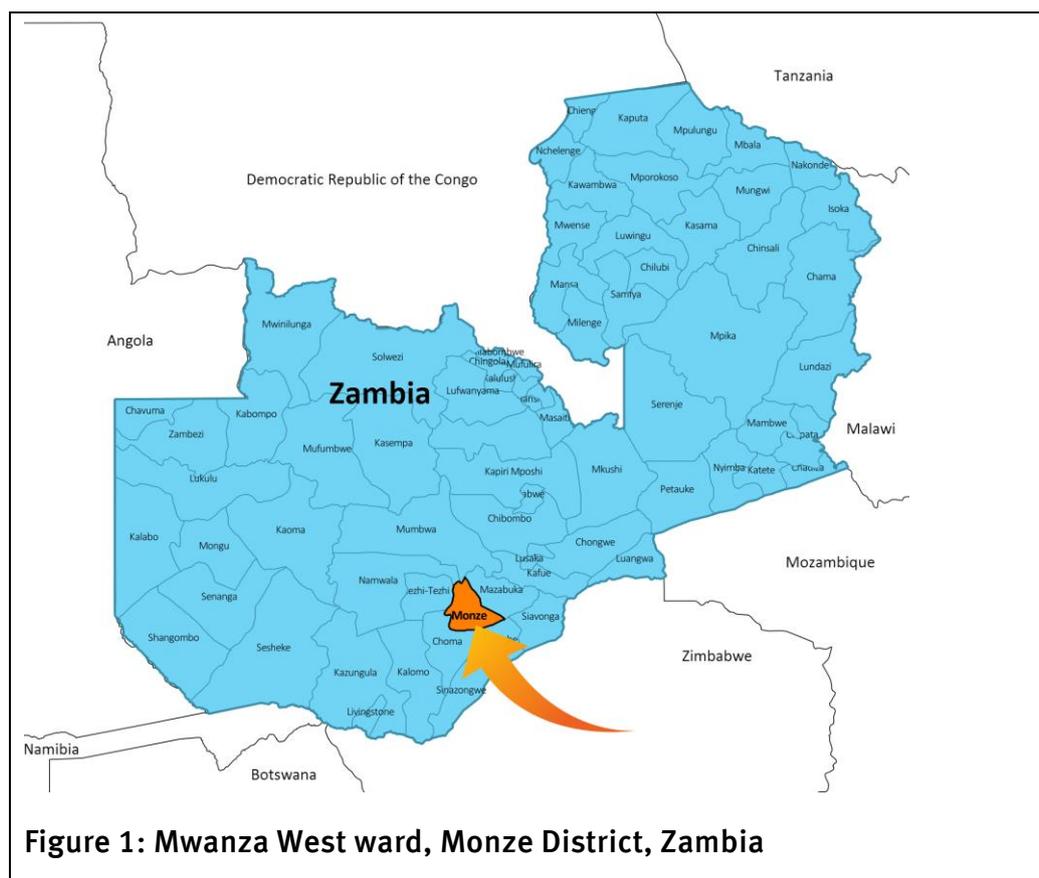


This report presents the findings of the pre-intervention baseline survey. The intervention and the mid-term review have been completed.

## 2 Methodology

The baseline data collection used a mixed-methods approach including both qualitative and quantitative data. The research began with a comprehensive literature review of all available information on vulnerable populations related to WASH in both peer-reviewed and grey literature.<sup>10</sup>

The study area was identified in consultation with WaterAid Zambia, based on plans to implement WASH programmes in the Mwanza West Ward, Monze District.



**Figure 1: Mwanza West ward, Monze District, Zambia**

### 2.1 Development of data-collection tools

A series of linked tools was developed to try to understand the full range of issues related to barriers to WASH (see Table 1). A review of published WASH methods showed that no established methods actually collected data that combined standard WASH information, access of vulnerable populations to WASH, and local and national policy and practice in the intersection of WASH and vulnerable populations. Therefore, a tailored set of tools (Tools 1–9) were developed for this baseline survey.<sup>11</sup> In this way, the resulting methods could then be implemented by other organisations to enable more data to be collected about the intersection of these two themes.

Table 1 gives an overview of the tools developed for data collection, the purpose behind their implementation, and sample typology and size (represented throughout this research as ‘n=’).

Table 1: Data-collection tools

Tool number	Tool name	Purpose	Tool description	Sample size (n)	Sample selection
Tool 1	Head of household questionnaire	Gather demographic data to enable comparisons between households with vulnerable and non-vulnerable members	Questionnaire about access to drinking water, hygiene and sanitation	128 households with vulnerable members, 116 households without vulnerable members	Clustered random sampling approach described in section 1.4 Data collection
Tool 2	Vulnerable Individuals questionnaire	Same as tool 1	Questionnaire regarding barriers faced by vulnerable individuals, and their perceptions and opinions of current WASH practices, additional to tool 1 questions	128 households	Same as tool 1
Tool 3	Key informant Interviews	To understand how vulnerable individuals fare within the community from a policy and practice perspective	Semi-structured interviews about access to drinking water, hygiene and sanitation for vulnerable individuals	Four people from senior government ministries overseeing WASH issues; six experts from WASH sector NGOs; four DPOs; two NGOs providing services to persons with disabilities; two NGOs providing services for older adults and chronically ill members (people with AIDS/TB)	

Tool 4	Focus group discussions	To explore perceptions, pursuing issues related to household and community access to WASH for vulnerable individuals	Discussions with community members, disabled people, older adults and members with chronic illness	Six groups with six to eight people per group	
Tool 5	Community Leaders interviews	To understand practice and perspective towards access to WASH for people with access limitations	Interviews with local officials/community leaders	Six community leaders	
Tool 6	Analysis of WASH facilities in Schools	To assess levels of accessibility of local school WASH facilities	Semi-structured interviews with teachers <sup>12</sup> from five schools and observation checklist of WASH facilities	Five schools	
Tool 7	Interviews with vulnerable Individuals	To have a deeper understanding of the barriers faced by vulnerable persons	Semi-structured in-depth interviews with vulnerable members	<b>UNKNOWN</b>	<b>UNKNOWN</b>
Tool 8	Latrine observation checklist	Analysis of the current state of household latrines	Structured observational checklist of household latrines	Eight households	
Tool 9	Waterpoint inspection tool	To provide information about the nature, state of repair and accessibility of existing water sources	Inspection of waterpoints situated in the communities in which tools 1–8 were implemented. Tool 9 supplemented data from tools 1, 2 and 5.	Eight communal waterpoints	Eight sources chosen in eight communities where tools had already been implemented

An initial round of in-depth interviews with people with disabilities (n=8), people with a chronic illness (n=8) and older adults (n=8) was undertaken to identify key issues and concerns about barriers to WASH faced by the local population (Tool 4). A series of linked tools was then developed, field tested and validated to explore the full range of issues related to barriers to WASH as components of this study. Tools 1 and 2 were developed to gather information from households with vulnerable members and compare these households with those in the immediate community which had no vulnerable people.

Tools 3–9 were developed to collect information about how vulnerable individuals understand WASH issues and to enable identification of issues related to broader community and national development policies and programmes. To address this, a range of data was collected from government ministries and local community leaders to better understand the elements that act as barriers to access for vulnerable individuals in the community, including public gathering spaces and in schools.

## 2.2 Implementation of data collection

Using a clustered random sampling approach, a list of villages of comparable size was drawn up, listed in alphabetical order and every third village selected for this study.

On the basis of population figures for the area, a sample size of 350 households was identified, in which 175 were to be households with one or more vulnerable member, and 175 to be a matched sample. Households with vulnerable members were identified using purposive sampling.

Each village had a village-level list of individuals who because of disability, chronic illness or older age, had already been identified by local village leaders to be eligible for assistance, although most did not currently receive support. These lists were used to identify ‘vulnerable’ individuals for interviews, focus groups and survey. The lists were in alphabetical order and every third name was selected until the target number of subjects was reached.

Because of practical field difficulties including identification, data collection and data entry, the final sample size after data cleaning was 244 households, of which 128 households had one or more ‘vulnerable’ members.

The rationale for collecting data in Tool 1 from both ‘vulnerable’ and ‘non-vulnerable’ households was that, although several studies have collected information regarding WASH or other development issues from vulnerable individuals and their households, comparable information is rarely available from surrounding households. Data were needed not only to identify what barriers to WASH exist in households with vulnerable members, but also to distinguish which WASH issues are related specifically to households with vulnerable individuals, and which WASH issues might reflect broader development concerns shared by all households in that community.

Households in the matching cohort were identified in a very practical way: the household without a vulnerable member nearest in line of sight from the doorstep of a household with a vulnerable member. Matched data were collected from a comparative sample of households identified in this way.

It is common in household surveys for the household head to provide information on all household members. Sometimes data are collected directly from a vulnerable member, but not general information on the household. In this study we sought to collect comparable information from heads of households (Tool 1) and from vulnerable members of the same household (Tool 2).

### 2.3 Additional data collection

After initial data collection and analysis, it was noted that there were several households in which one or more members reported providing a substantial amount of assistance to the vulnerable individual. A follow-up series of focus groups with these family members, known as the primary caregivers (n=71), was undertaken to better understand the nature of these individuals' roles and the effect that such assistance had on other household responsibilities.

### 2.4 Data analysis

Data were collected in-country, in cooperation with WaterAid Zambia and INESOR. Quantitative and qualitative data were collected and then entered in-country by INESOR, supplemented by observational information on toilets and waterpoints collected by WaterAid Zambia staff.

Data entry was in SPSS. Initial transcription of qualitative interviews was done by INESOR. Qualitative and quantitative data were sent to LCDIDC in London for further analysis. The quantitative and qualitative components were analysed and then merged, re-analysed and then shared with WaterAid, WaterAid Zambia, WEDC and INESOR for further analysis.

Ethics approval for the project was sought and obtained through UCL and by INESOR through an independent ethical clearance committee.

### 3 Findings

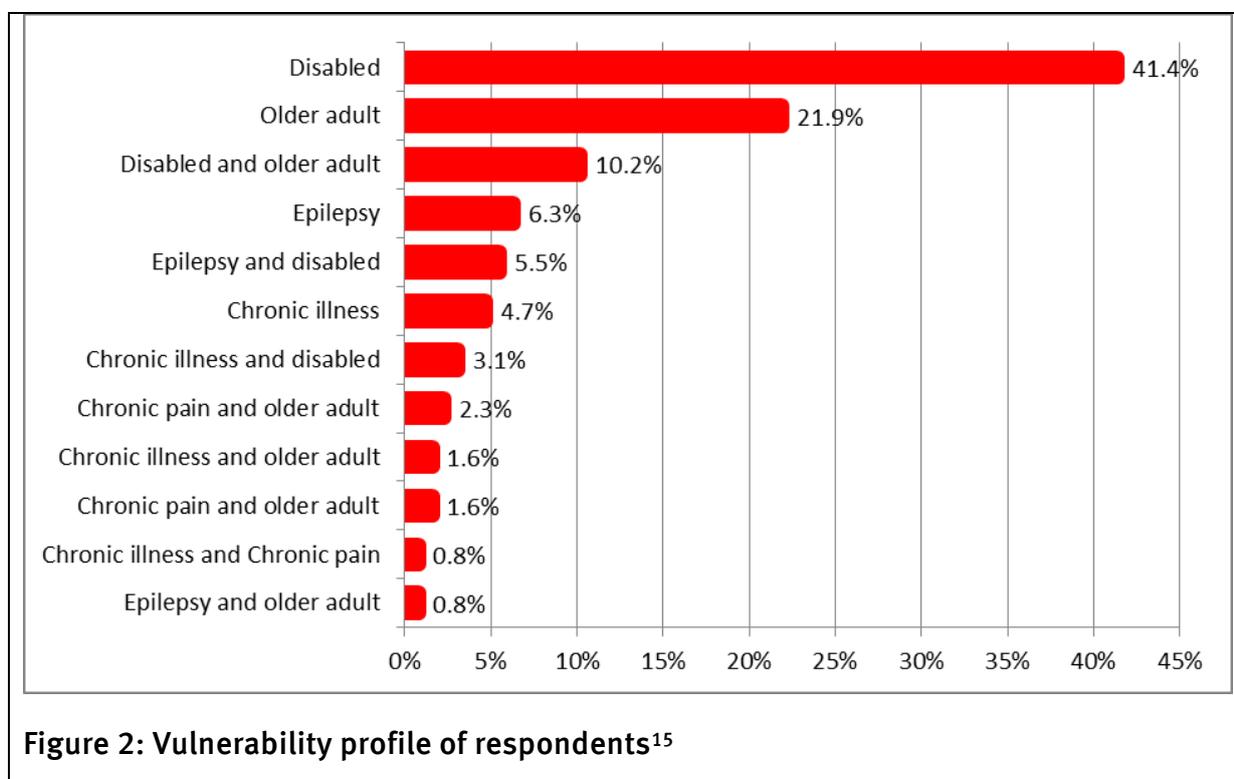
#### 3.1 Demographics

Mwanza West Ward is a rural, largely agricultural area. Homesteads dot a relatively flat, rolling landscape with several growth centres.<sup>13</sup>

Respondents to the head of household survey were balanced by gender and had a mean age of 47 years. 59% reported themselves as married, 20% widowed, 13.5% unmarried and 6% divorced. On average there were 6.7 members per household. Of the 244 households surveyed, 128 households (52.5%)<sup>14</sup> had a member who was disabled, chronically ill or was an older adult; 116 (47.5%) did not. All except two of the 128 households had just one vulnerable member.

#### 3.2 Types of vulnerability

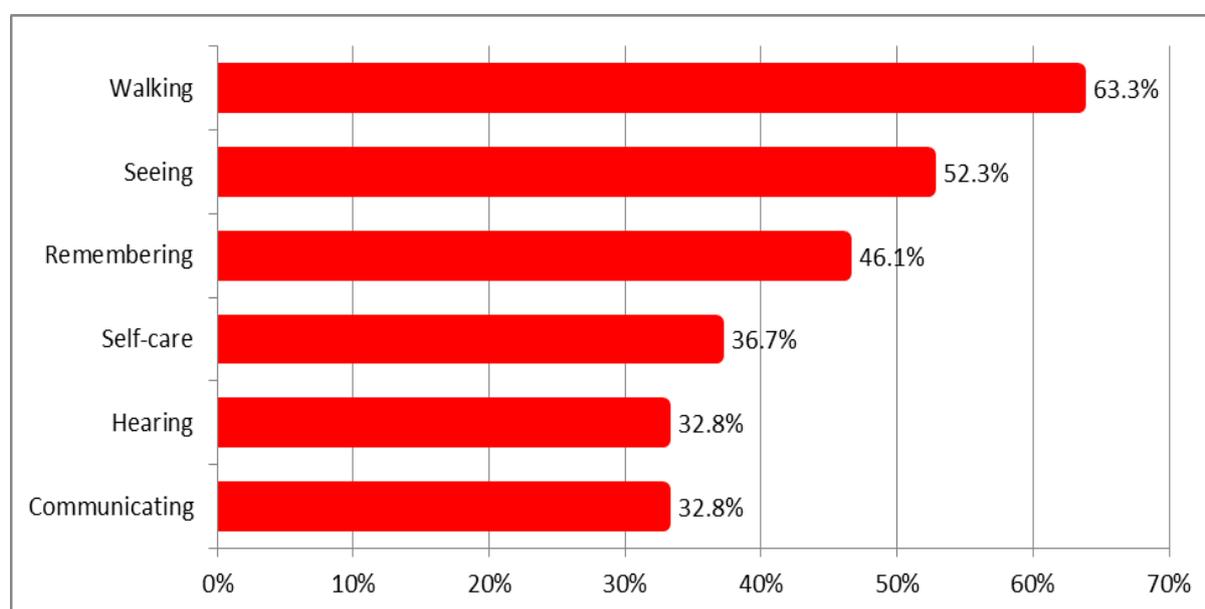
As Figure 2 shows, disability was the most commonly reported condition among vulnerable individuals. 53 respondents (41%) identified themselves as having a disability; 28 (22%) indicated that they were frail because of old age, and 13 (10%) stated they were both disabled and older. Eight people (6%) identified themselves as having epilepsy, which was considered distinct from a disability. 26 people (20%) identified an additional combination of these limitations.



The profile of households with vulnerable members is slightly different from those of households without vulnerable members. This reflects the fact that people with disabilities, older adults and chronically ill people are more likely to be female, older and/or unmarried if they are living as a member of an extended family household rather than heading a household of their own. Members of households with vulnerable members are, on average, significantly older than are members of households without a vulnerable member. However, as one of the vulnerabilities considered is “old age”, this is to be expected.

63% of vulnerable individuals were women. Vulnerable individuals had a mean age of 53.1 years. 17% were married, 38% were unmarried, 7% were divorced and 37.5% were widows or widowers. Again, the relatively high rate of widowed individuals reflects the fact that old age was one of the vulnerabilities included, and the fact that older widowed relatives might be more likely to join the households of their children rather than maintain separate households.

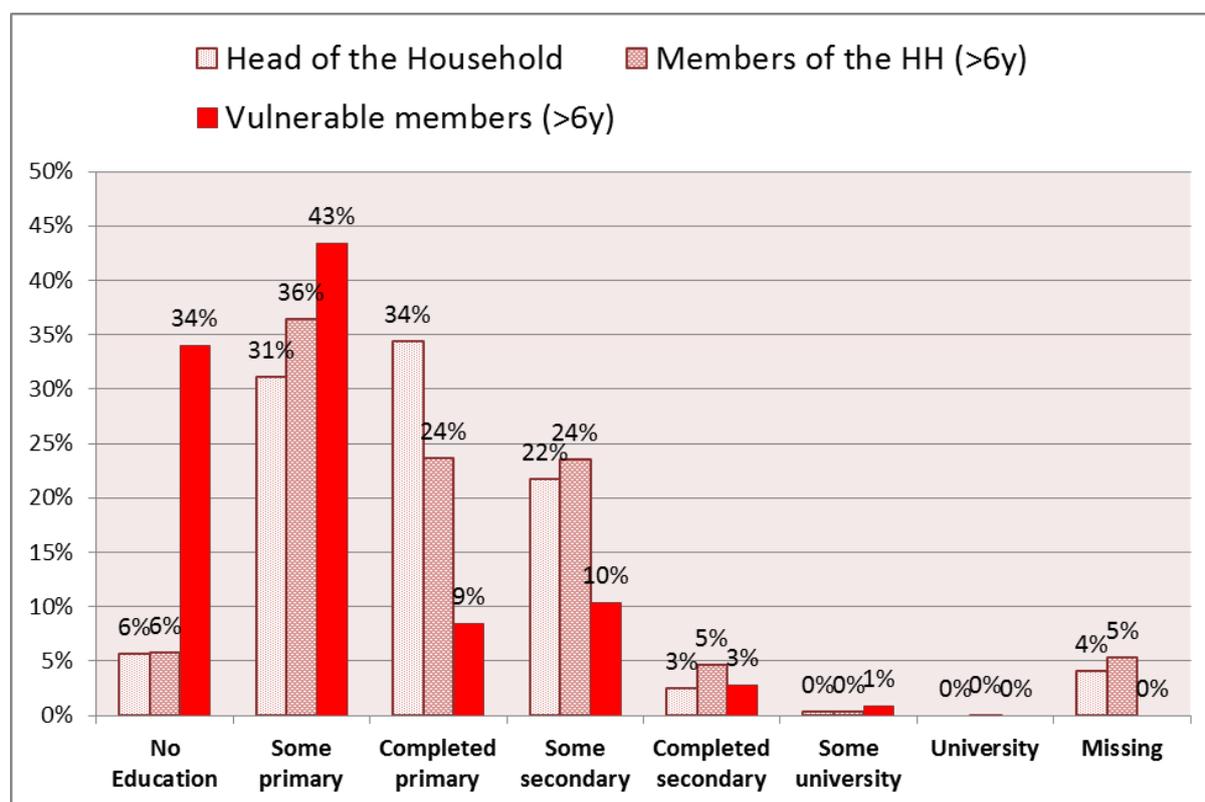
When responding to the questions about activity limitations that have a direct bearing on their ability to access WASH services, 95% of the vulnerable respondents stated they have at least some difficulty in one or more domain (seeing, hearing, walking, remembering, self-care, communicating). 79% reported having ‘a lot of difficulty’ or ‘cannot do it at all’ in at least one of the specified domains. These are shown in Figure 3.



**Figure 3: Limitations in activity.**

Of the vulnerable individuals surveyed, 41% stated they use, or would benefit from the use of, some type of assistive device. 24 (45%) of those who use an assistive device use a cane, 15 (28%) are wheelchair users or would use a wheelchair if available, five (9%) use crutches, and two use other mobility devices (trolley, walker). Only one person uses a hearing aid and one mentioned glasses. The others (n=6) did not specify the type of device.<sup>16</sup>

Education levels of vulnerable individuals were substantially lower than were those of the head of household or other household members (Figure 4). 34% of vulnerable individuals reported having had no formal education, compared with 6% of other household members. 43% stated having had some primary education, but only 8.5% had completed their primary education compared with 34% of heads of household. Only 14% had some education beyond primary school, compared with 39% of household heads.



**Figure 4: Level of education of vulnerable individual versus heads of household and other members of household.**

Such differences in levels of education could reflect several factors, such as lower school attendance rates among people with disabilities and lower rates of school attendance for girls than boys, especially in older generations. It is also possible that there is an inherent bias in household composition. Vulnerable individuals with more education might be more likely to be economically self-sufficient and thus more likely to head their own household rather than join households of relatives.

The main source of income for most households surveyed (80%) was agriculture. Some reported their primary household income to be small business or trade (9%), craft (2%) or manual labour (3%). 6% reported their income as ‘other’ but did not specify what (Table 2).

Only 22 out of the 128 (17%) vulnerable persons interviewed reported that they contributed directly to household income through agriculture, although a smaller

number undertook waged labour through trade, craft or manual labour (Table 2). 35% reported that they routinely performed unpaid tasks (agriculture, cooking, cleaning, watching animals and children, fetching firewood and water) that contributed directly to household wellbeing.

Occupation	Percentage
Agriculture	80%
Trade	9%
Craft	2%
Manual Labour	3%
Other	6%

**Table 2: Primary sources of income**

### 3.3 Access to water at the household level

Heads of households reported that their main sources of drinking water in both rainy and dry seasons are boreholes (categorised as protected sources) – 52% for households with vulnerable members, and 49% for those without, and wells (categorised as unprotected sources) – 41% and 43%, respectively. The remaining households collected from other unprotected sources including rivers, streams and from surface water (ponds) or springs. However, this picture might be more complicated for vulnerable individuals who do not live in households where someone can fetch water.

There are slight differences between case and control households. Table 3 presents information about the general sample, and Table 4 shows data disaggregated by households with a vulnerable member (case households) versus households without a vulnerable member (control households).

Data from the Water Source Inspection Tool (Tool 9) show that six of the eight waterpoints surveyed were boreholes and two were dug wells. The distance of waterpoint to the nearest house was recorded in six cases – this ranged from 100m to 500m. The accessibility of the paths to the waterpoint was assessed and the results represented in Table 5. An assessment of the state and functionality of these waterpoints was also carried out and presented in Table 6.

Type of path surface		Path terrain		Obstacles or trip hazards, e.g. rocks, vegetation, rubbish, etc.	
Firm	1	Flat	1	No barriers/obstacles	6
Partially firm	0	Reasonably level	4	Minor barriers	0
Partially muddy	0	Up and down	2	Obvious barriers, some difficulty likely	1
Extremely muddy	0	Very hilly	0	Major barriers, hugely difficult or impossible	0
Missing data	7	Missing data	1	Missing data	1
Total	8		8		8

**Table 5: Accessibility of paths to waterpoints**

Waterpoint functionality		State of waterpoints		Presence of Water User Committee and active caretaker	
Functional	7	Clear of standing water	4	Active presence	6
Non-functional	0	Presence of obstacles: Fences, steps, and narrow entrances	8	No presence	2
Missing data	1	-	-	-	-

**Table 6: Assessment of waterpoints**

These waterpoints are considered to be stable water sources in this area: 41% of respondents reported having ‘always’ used the same water source, and 39% of respondents have been using their current source of water for five years or more. Both household heads and vulnerable individuals report using the same primary water sources at comparable rates throughout the year.

74% of household heads surveyed report that there is no monthly or annual fee for water from the protected sources. Those who do pay for water (12%) report paying an annual maintenance fee, or an additional charge relating to regular water use.

Where there is a water fee, if respondents cannot afford the cost, 17% (n=14) stated they use less water. Most stated that they continue to use protected water sources without paying, the assumption being that ‘the community understands’ because they are old or disabled. However, 28% (n=17) admitted sometimes supplementing the water from the protected sources by using ‘other’, unprotected sources when they cannot pay or when the protected source is far from the house and they are pressed for time.

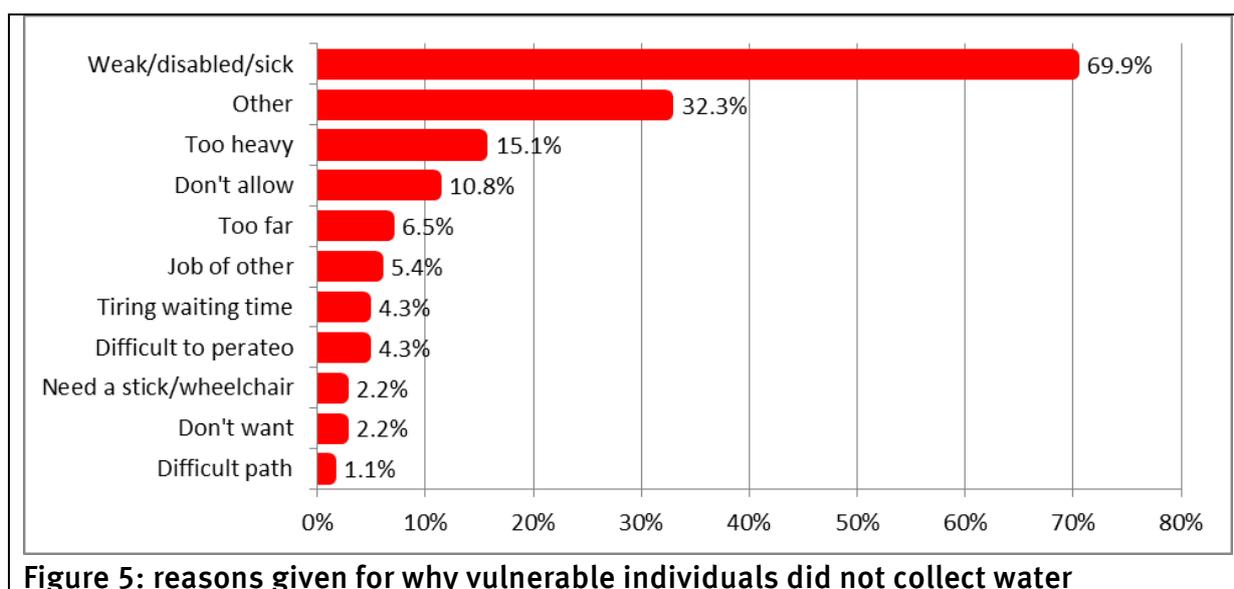
Responses from vulnerable individuals indicate that use of water from unprotected sources might be more regular than commonly acknowledged.

### 3.3.1 Barriers to water collection for vulnerable individuals

Water collection is generally by one or several individuals for their household. 52% of vulnerable individuals reported being unable to fetch water themselves. One older woman summarised the situation reported by many, saying:

”If a person is disabled, if the legs are not OK, that person cannot manage.”

The main reason given by vulnerable individuals for not fetching water related to the physical limitations associated with their vulnerabilities: 70% gave being weak, disabled or sick as the reason (Figure 5). 32% of respondents listed ‘other’ reasons, but in interviews and focus groups, these other reasons seem to fall largely into the category of ‘fragility’ linked to a disability, chronic illness or old age. Many households reported that fetching water is beyond the abilities of the vulnerable family member. In some cases, for example people with epilepsy, there was a concern that an individual might have a seizure and fall into the well.



Many faced a combination of barriers. In addition to individual impairments, a series of environmental barriers were identified:

- **Paths:** Paths that were slippery, steep or had uneven surfaces made collecting water difficult or impossible for some vulnerable individuals.
- **Distance:** Water sources far from the homestead made water collection difficult for some.
- **Design of protected source:** Handpump handles that are out of reach or too high or heavy to move easily, and lack of raised area on which to rest buckets and pots.

- **Time spent waiting for water:** In interviews and focus groups, several vulnerable informants reported that when there is a queue at the pump they are often not allowed to go before others, even when it is difficult for them to stand for long periods.
- **Carrying:** Several informants reported difficulty carrying as much water as needed back to the house because of the weight of the container. Some had to make more than one trip to the water source to collect enough. Others reported constraints on using water because of their inability to carry enough back.

Significantly, most vulnerable individuals and members of their households thought their physical limitations were the main barriers to WASH access, i.e. that the ‘problem’ lies in the individual. Few of those interviewed identified environmental, attitudinal or institutional barriers that might prevent vulnerable individuals from being able to collect water themselves. For example, although several informants cited environmental barriers, such as the weight of the water container, or inaccessible pathways, or difficulty operating the pump, no-one recognised that these barriers could be modified or changed.

Attitudinal barriers were also an issue. 3% of vulnerable respondents reported that they had been told not to touch water or handle water because some members of the community thought them unclean or their condition was contagious (Figure 5).

These findings very much reflect the individual model of disability; when disabled people, their families and communities are not aware of the possibility of making waterpoints easier to access, they will not see access as a barrier. This points to lack of information, lack of exposure to different possibilities, designs and approaches that could enable more vulnerable individuals to collect water themselves.

Individuals who do not fetch water rely on other members of their households. Fetching water is a task often shared by many members of the household: adult female and male heads of the household are generally in charge of fetching water, followed by female children. Older men in particular report seeing this chore as something that younger children and adult females were primarily responsible for.

According to household heads, 45% (n=58) of vulnerable individuals in their households fetch water. A similar figure was reported by vulnerable members of the household, 48% stating that they routinely fetch water.

However, 55% (34) of vulnerable individuals who report fetching water report facing a series of substantial environmental, attitudinal barriers and institutional barriers when doing so.

### 3.3.2 Use of alternative sources of water

Several vulnerable individuals in interviews and focus groups reported living in households no one was physically able to easily fetch water. Their options were more limited and the situation becomes more complex.<sup>17</sup>

Many reported having to wait for someone to come by to fetch water for them. Some relied on extended family. An older woman with a physical disability shared her thoughts:

“Now because of the leg, I fail to lift even a small container to bring home (water) to drink. Before you see a grandchild, you just stay like that, there is no one to fetch for you.”

Many called upon passing children but reported that relying on children to fetch water has its problems. Children often take ‘short cuts’ and collect water from the nearest, potentially unprotected, water source rather travelling further to a protected source. As one older man explained:

“But these children, you see when the distance is too much for them, they just fetch from the nearby stream. Me, mostly I drink water from the stream which is dirty due to the young age of the children who fetch water”.

Another older woman with a physical disability, who relies on children on their way home from school, also reported that this assistance was unreliable:

“I see someone’s child to fetch water for me, even yesterday, the sun set without water, there was no one to give me water. I couldn’t find anyone.”

Although it was widely acknowledged that using unsafe water from a pond or stream presented a health risk, interviews and focus group discussions revealed vulnerable individuals use water from such sources. It is interesting to note that this use was not reflected in the quantitative data, perhaps indicating that in some households, although the primary source of water might be from protected boreholes, this is supplemented when necessary by more easily obtainable shallow well, pond or stream water.

The response might also reflect the fact that effective public health campaigns in the area seem to have educated the local population well about the health threats that unsafe water represents. Informants might therefore have been reluctant to admit use of unprotected water sources in a survey, but are willing to discuss the subject when raised by others in focus groups. Vulnerable members of the community stated that water from unprotected sources (e.g. ponds or shallow wells) often ‘looks dirty’ or ‘looks cloudy.’ Several also commented on the presence of insects, frogs, dirt and other unidentifiable ‘particles’, but felt they had few alternatives so had to use it.

One head of household explained that a family member with a physical disability uses an unprotected water source near his home:

“I have (one) who is lame ...when left alone at home there is no one to give water, such that the shallow well we dug at home, he gets water from there.”

Another man with a physical disability broadened the discussion by noting that, at times, he and members of his household use unprotected water sources:

“We drink dirty water because even germs are found, the frogs are also found. There is no chemical we put in to protect us from water issues. We just fetch to drink because where we fetch is far.”

An older woman explained she worries about the water she both drinks and bathes in from an unprotected water source nearby, but that she has few alternatives:

“The water we drink is not safe and where you bathe, it irritates...The water is dirty and whitish. The frogs also die in there. They die even if we drink, because the water is from dirty (shallow) wells.”

For some vulnerable individuals, having others fetch water involves a cost. Several informants reported giving ‘a bit of money’ or ‘some food’ to a child in return for their willingness to fetch water.

At the most extreme, some vulnerable individuals went thirsty. One older woman summarised much of the preceding focus group discussion by saying:

“I fail to fetch water, when you age, you do not manage...You can only use your mouth to say ‘give me water.’ There is nothing that works on you – even the knees are paining. Just nothing. The legs pain, walking is a bit of a problem.”

Another older woman said:

“I need water to drink, eat and clean myself every day. Yet I live alone and can’t walk.”

A blind woman told the interviewer:

“Yesterday I got so thirsty. The young ones ran away, they do to play. Us, now we are blind, we can’t manage to fetch water.”

An older man added:

“I have a water problem because water is found, is five kilometres. So fetching water is hard. Before you find someone to help you, who helps you? It is to stay thirsty. There is nowhere you can find water, even if you want water to drink you just stay thirsty because water is far.”

Vulnerable individuals in households where there is no one else to fetch water also report having to weigh carefully who they ask, and how often they ask these people for help. As collecting water is a daily activity and not a one-time gesture, there is a concern of ‘overtaxing’ a family or neighbour support system.

There are costs, either in terms of money or food or in terms of calling upon social networks. These are regularly taken into consideration whenever vulnerable individuals need to ask for help in collecting water. These factors may limit the amount of water used, as discussed below.

### 3.3.3 Adaptations to improve accessibility to water

Despite difficulties encountered by so many informants in fetching water, when asked if any changes could be made to improve accessibility, most informants could only suggest that a protected water source is installed much nearer to their own homesteads. Smaller-scale changes and less costly adaptations, such as changes in design of paths, type and weight of water buckets or adequate accessibility of borehole or handpumps were not raised. Interestingly several informants had heard about adaptations to handpumps, but had not considered adaptations locally. For example, one older man told the focus group about an accessible handpump he had seen:

“The only place I saw it is in Kayuni. In Kayuni, the handpump where you hold is the same height as the disabled. It has a chain when you are pumping water into the container. So that one is good because to the disabled, it can be good to us.”

### 3.3.4 Access to drinking water within the household

Concerns about access to water continue when water has been brought into the household. Importantly, almost all heads of households that included at least one vulnerable member stated that the vulnerable member uses the same source of drinking water (96%) and the same amount of water (92%) as all other members of the household. Vulnerable members of these households agreed (98% same source, 95% same amount). There was also agreement among household heads and vulnerable respondents (95.5% and 95%) that all the members of the household have enough drinking water.

However 22% (n=28) of all vulnerable individuals (one in five) reported being in households where drinking water was not easily accessible, because water is stored on shelves that were too high for vulnerable individuals to reach, kept in jugs or jerry cans too heavy for them to handle or in containers (such as pitchers or bowls) that required dexterity in picking up and pouring that many vulnerable individuals lack. There was often no one at home to help them reach drinking water when needed.

Those who cannot get water for themselves within the household reported having to wait for others to help them get drinking water. Of those who needed help, three quarters (78%) said that they regularly had to wait for help from others. In interviews and focus groups several also reported that they hesitate to ask for water or refrain from asking for water as frequently as they would like, because there is no one to help them or because they do not want to over-burden primary caregivers or other household members by asking for help too frequently.

Of the 23 vulnerable individuals who responded to the question 'What could be done to change the availability of water in the household?' 65% said 'nothing' or 'nothing I am too old.' Another 30% reported having a tap in the yard as the most effective improvement, but offered no additional comments. One caregiver believes the issue was her responsibility 'always remembering to give him because he can't do anything by himself' and another vulnerable individual thought an adaptation would be 'somebody to be home' throughout the day.

Only 13% (16 out of 128) of these vulnerable individuals suggested different storage arrangements for water. Few adaptations were observed or reported in accessing water in the home. When asked whether they could think of any solutions that would make it easier for them to access stored drinking water within the household, only a few household heads and vulnerable individuals responded. Their answers included providing smaller containers, moving the stored water to lower shelves or on to the ground, or moving the stored water closer to the vulnerable individual. Few had actually instituted such adaptations in their own homes.

This is a striking finding. Clearly, there is little knowledge or awareness of alternative low-tech, low-cost solutions or inclusive designs that could both allow more autonomy and choice for vulnerable individuals and free other household members from unnecessary chores. Although difficulty in accessing stored water within the household is an environmental barrier, 86% of vulnerable household members who reported difficulties attributed this difficulty to their own physical limitations. This finding reflects those under section 3.3.1. Another 11% reported 'other' reasons, but, when queried, the 'other' category also pertained to perceived individual limitations. "I am blind," said one old woman, for example, "It is difficult for me to move across the room." Only one vulnerable individual and none of the household heads reported that the problem was with the system for water storage and access within the household.

### 3.3.5 Water treatment

One additional finding should be noted in relation to drinking water. Although most households did not treat drinking water after it was brought into the household, there was a difference in water treatment patterns between households with and without vulnerable members (Table 7). 18% of households without a vulnerable member treat water either by boiling it or adding Clorin.<sup>18</sup> The number using treated water fell to 6%

among households with vulnerable members (7% versus 3% used boiled water; 11% versus 3% used chlorinated water), as seen in Table 7.

Type of drinking water		Condition		Total	
		Households with vulnerable members	Households without vulnerable member		
Untreated	Count	119	94	213	
	%	93.7%	81.7%	88%	
Boiled	Count	4	8	12	
	%	3.1%	7.0%	5%	
Chlorinated	Count	4	13	17	
	%	3.1%	11.3%	7%	
<b>Total</b>		<b>Count</b>	<b>127</b>	<b>115</b>	<b>242</b>

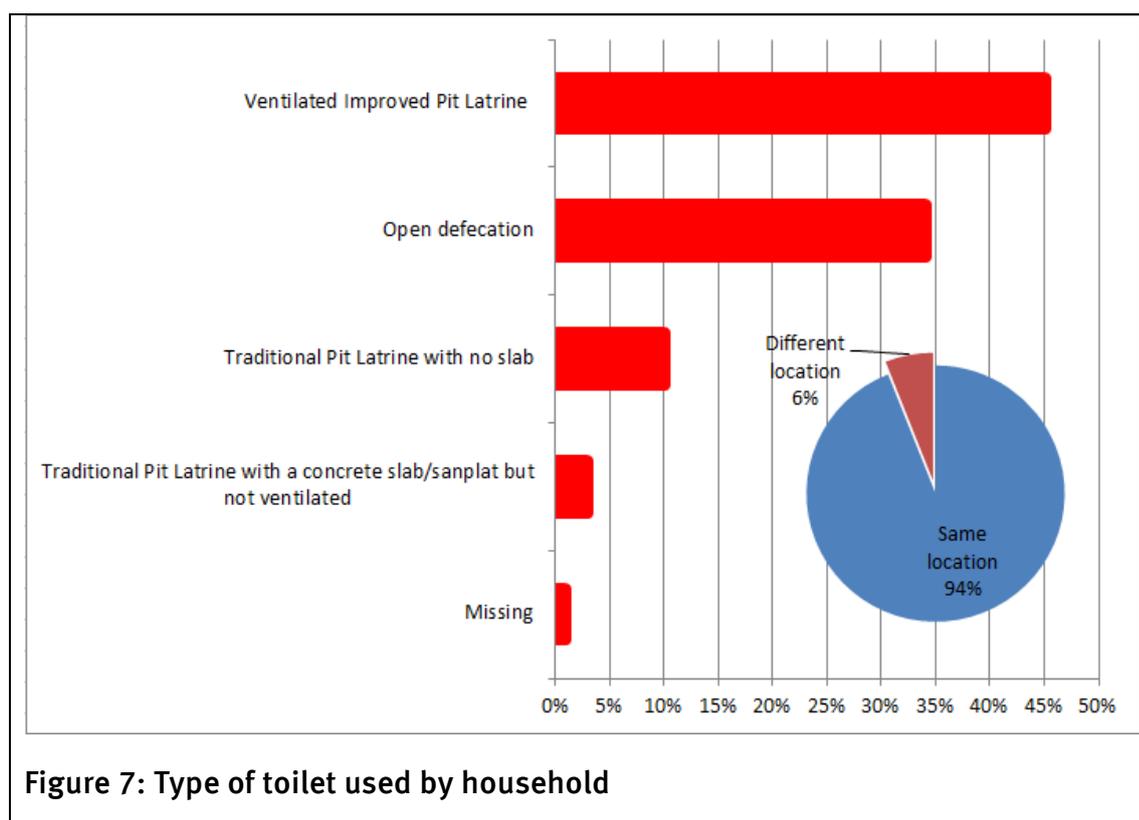
**Table 7: Type of drinking water – treatment by report of household head**

This is an interesting finding given the fact that levels of education, income and access to health information are similar for people in households with and without vulnerable members. One explanation for this discrepancy could be that adult women who are primarily responsible for household chores such as boiling or chlorinating water also act as primary caregivers in most households with vulnerable members who need assistance.<sup>19</sup> In households where they act as primary caregivers these women might have less time for other household chores such as treatment of drinking water. This will be discussed in greater length in the section on caregivers.

### 3.4 Access to toilets and sanitation facilities

#### 3.4.1 Type of toilet

64% of all households had access to a toilet, and 36% had no toilet and practiced open defecation in nearby bushes or fields. Of the 64% who indicated that they have access to a toilet, 65% stated that they share toilets with other households. On average, household heads reported that nine people share a toilet. The household toilet is generally located within the household compound (54.5%) or in nearby fields or bush (36%).



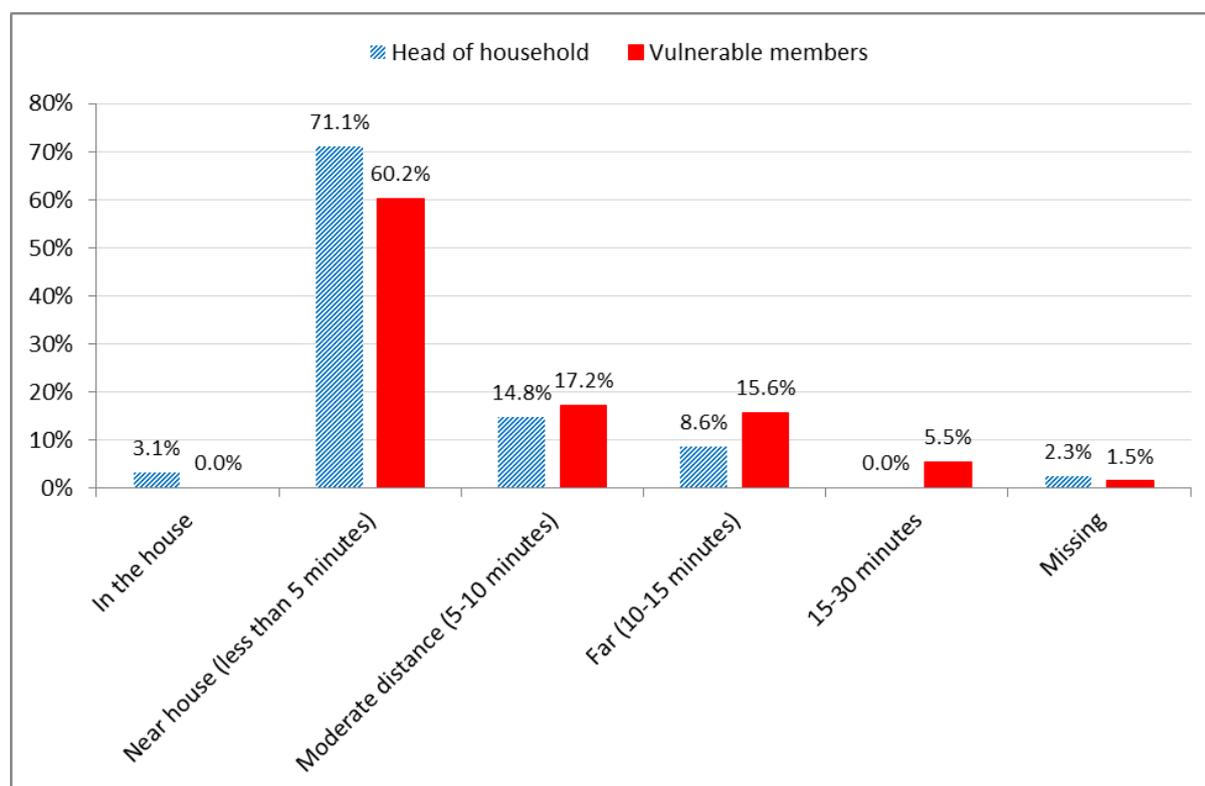
According to the heads of households, usually all members of the household, both those with and without vulnerable individuals, use the same toilet or location for defecation (96%). In a few cases (4%), different arrangements were reported by household heads. These were usually related to children, who use the yard or the bush behind the yard.

Vulnerable individuals' responses were somewhat different. 84% of vulnerable individuals (compared with 96% of household heads) stated they use the same latrine or open defecation site as other family members. 16% (versus 4% reported by household heads) said they use a different arrangement. This discrepancy appears to be because some vulnerable individuals use open defecation sites or other alternatives regularly basis rather than use the shared family locations. Discrepancy within households might also reflect the fact that vulnerable individuals alternate between using the family latrine and using the bush when the family latrine is crowded or dirty. It might also be the case that household heads pay little attention to the toilet habits of vulnerable individuals in their households.

### 3.4.2 Barriers to accessing the toilet

The reasons why vulnerable individuals use different toilet arrangements appear to be in response to a combination of environmental, attitudinal and institutional barriers. For many vulnerable individuals the decision to use an alternative site rather than the common family site might be because more time and energy is required for them to

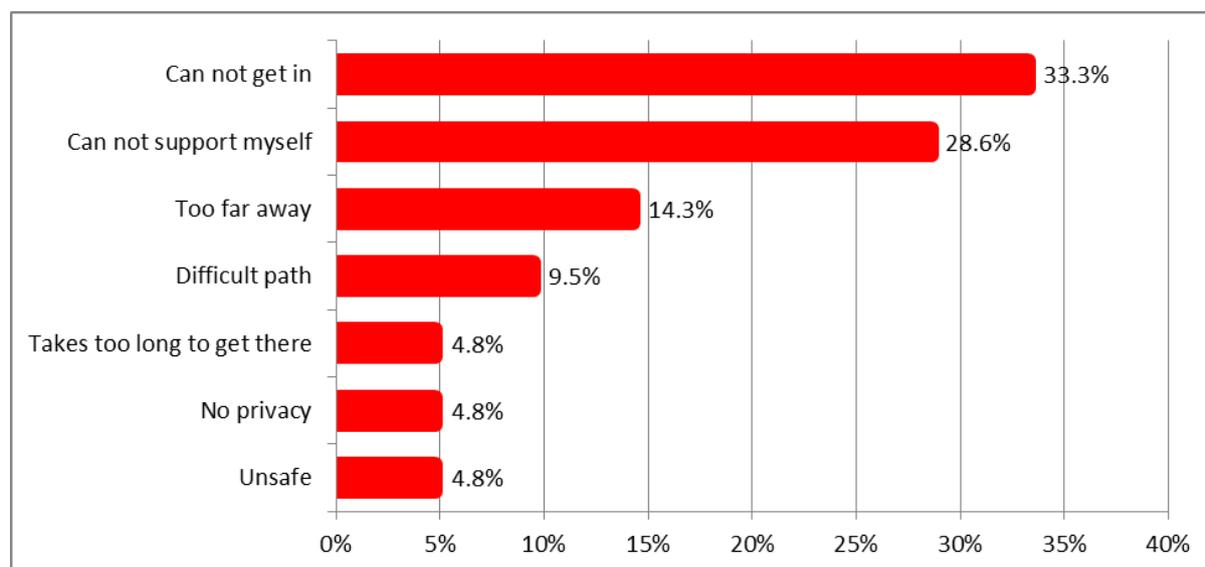
reach the family toilet compared with other household members. 74% of non-vulnerable household members report needing five minutes or less to reach the toilet, compared with 60% of vulnerable people who can reach the toilet in that time. 8.6% of non-vulnerable people reported taking ten to 15 minutes or more to reach the toilet and none reported needing more than 15 minutes. This finding was backed up by the Household Latrine Observational Check List (Tool 8). In 15 of 20 cases (75.5%) for non-vulnerable members of the household, the distance between the house and the toilet can be covered within five minutes. In two cases (10%) people need five and ten minutes to reach the toilet. One case (5%) needed between ten and 15 minutes and in two cases (12.5%) more than 15 minutes are needed. This is in contrast to the 21% of vulnerable individuals who report needing ten to 15 minutes or more (Figure 8).



**Figure 8: Time needed by vulnerable versus non-vulnerable members of same household to reach toilet**

A third (33%) of vulnerable individuals said they use an alternative arrangement to that used by other family members for several reasons: because they could not get to the toilet, or it is difficult to reach because paths were often too slippery, too steep or otherwise too difficult to navigate; or toilets were too small to enter for people using crutches or wheelchairs. Almost a third (29%) reported it being difficult or impossible to support themselves once inside the toilet – no grab bars, stool or chair, or other adaptations were available that would enable them to position themselves comfortably. Several individuals also mentioned the need to crawl across a dirty latrine floor or open defecation area. These factors deterred them from using the same place other household members to defecate as. For people with visual impairments, finding their way back and forth to the toilet was another concern. Additional barriers were

lack of privacy and sharing communal toilets with people who then accused vulnerable individuals of being ‘unclean’ or taking ‘too long’ (Figure 9).



**Figure 9: Difficulties encountered in using household toilet<sup>20</sup>**

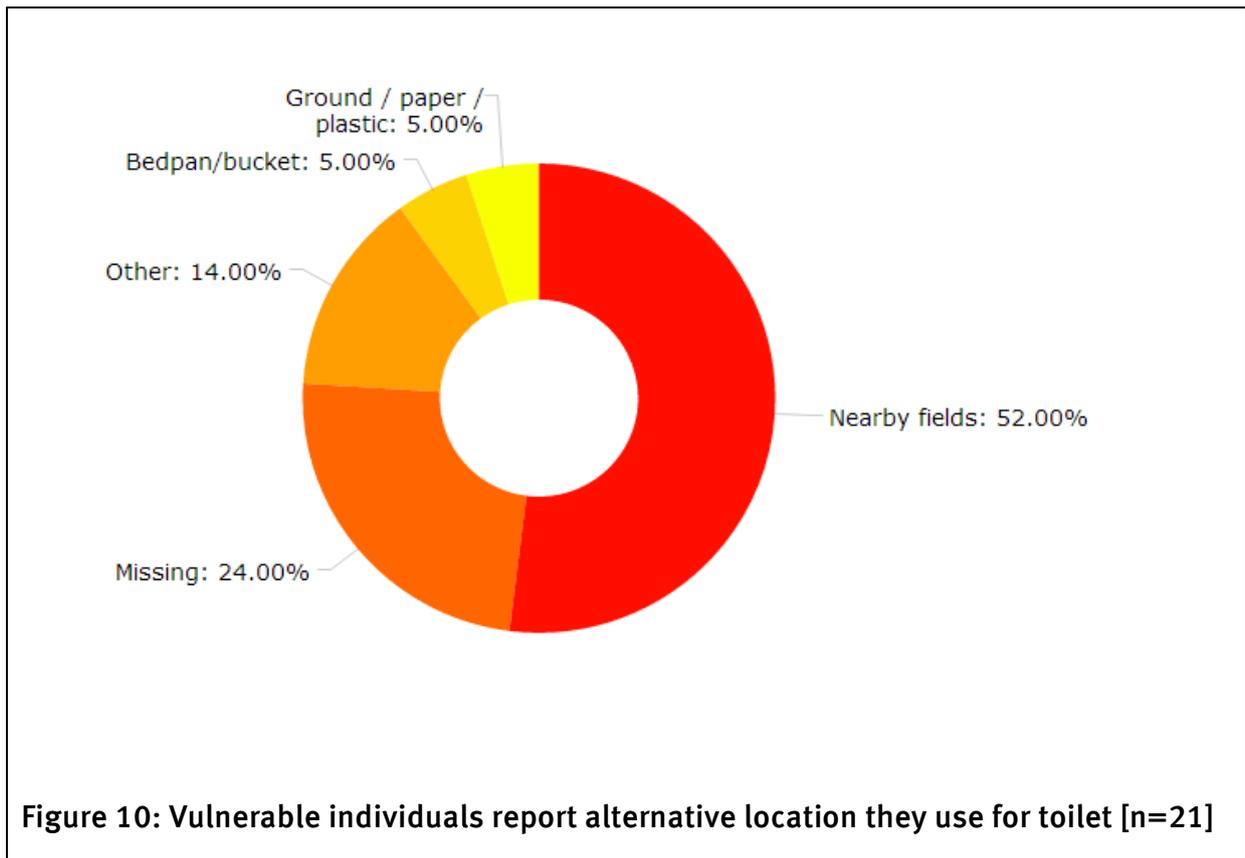
The qualitative data provided additional insight into issues. Difficulties with latrine structure (e.g., too small, too dark inside), squatting without support and distance to toilets are recurrent themes in focus groups and interviews. For example, an older woman reported:

“I can’t walk long distance due to separated bones; I have trouble such that when I sit, I sit only on one side. It is likely that sometimes you can wet yourself.”

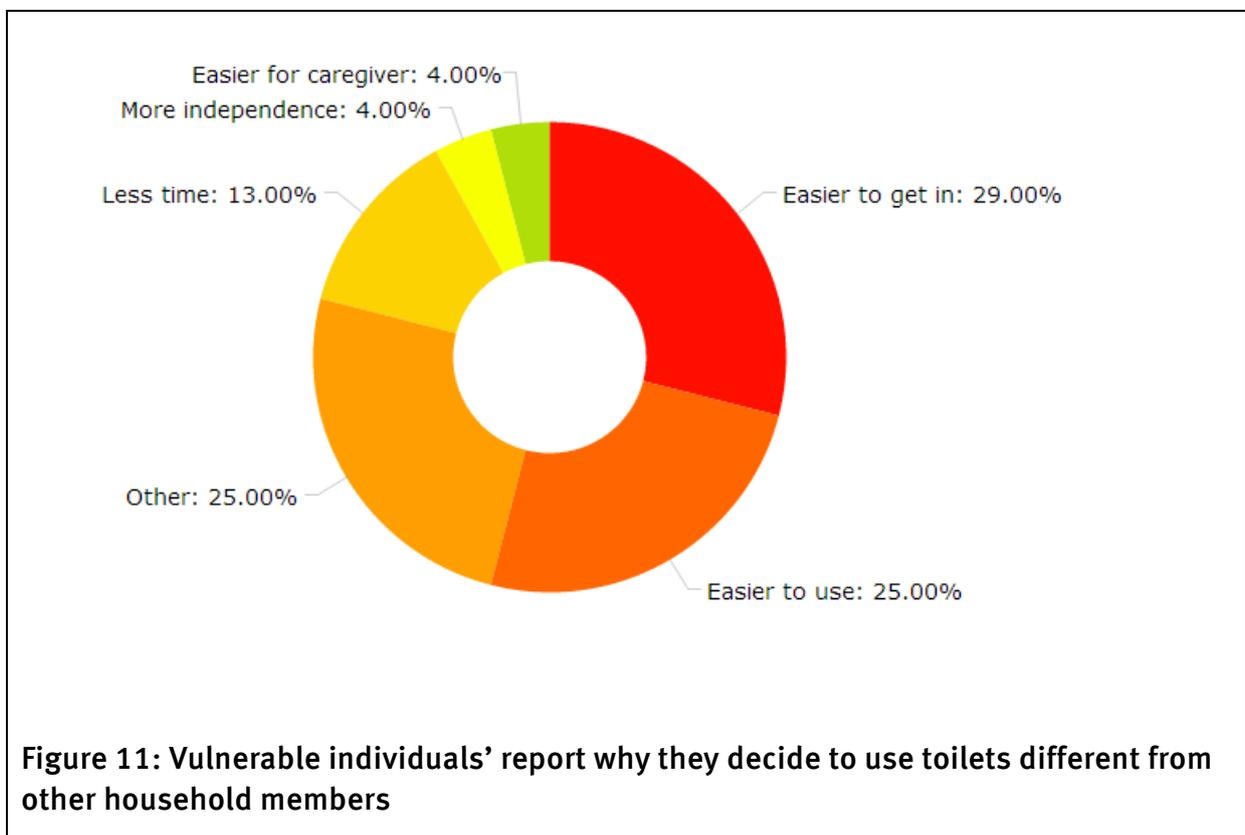
The moderator of one session added an anecdote based on his own experience:

“There is one child we found who has ten years. Ten years but she is not growing. She said those toilets they make...I don’t go. I fear to drown (to fall in).”

Only a few individuals (10%; n=2) used paper or plastic on the floor, or a bucket within the house. These individuals generally needed the assistance of someone else in the household to hold or support them while they defecated and then to dispose of the faeces (Figure 10).



Several also said alternative arrangements ‘allowed more independence’ or made it easier for caregivers (Figure 11).



As was true for accessing water within the household, household heads and vulnerable individuals both reported that problems lay with their own physical limitations in accessing latrines or open defecation sites, rather than identifying barriers with how the latrines or open defecation areas are configured or maintained. “I cannot go so far.” said one man with AIDS. “People yell at me if I take too long in the toilet,” said an older, frail woman.

### 3.4.3 Open defecation – key issues and concerns

It was noted in focus groups and conversations with vulnerable individuals that several vulnerable people apparently alternated between using the bush and using their household latrine. Comments in discussions with household heads and interviews with community leaders indicate that many vulnerable and non-vulnerable people continue to practice open defecation at times, particularly when working in the fields or travelling away from home. For vulnerable groups, latrines were used when there was someone at home to help them or when things were not too busy in their households. Otherwise, they would resort to open defecation.

Levels of open defecation might therefore be higher than indicated by data from the questionnaires (Tools 1 & 2). This is discussed in section 5. Open defecation raises several concerns, some of which are shared by both vulnerable and non-vulnerable individuals. For example, lack of privacy is a concern for all. Privacy was an issue consistently raised in interviews and focus groups. 26% (n=28) of all vulnerable individuals interviewed reported that they were unhappy with the level of privacy that their toileting arrangements allowed. A particular concern was the inability of individuals with physical limitations to walk or crawl far enough into the bush to maintain privacy. For example, one man reported that “When the bush is burnt, I don’t manage to go far because I don’t walk properly”. Unable to use his family latrine and unable to walk to a place with bush for privacy, he was forced to defecate in full view of others, and found himself teased and ridiculed.

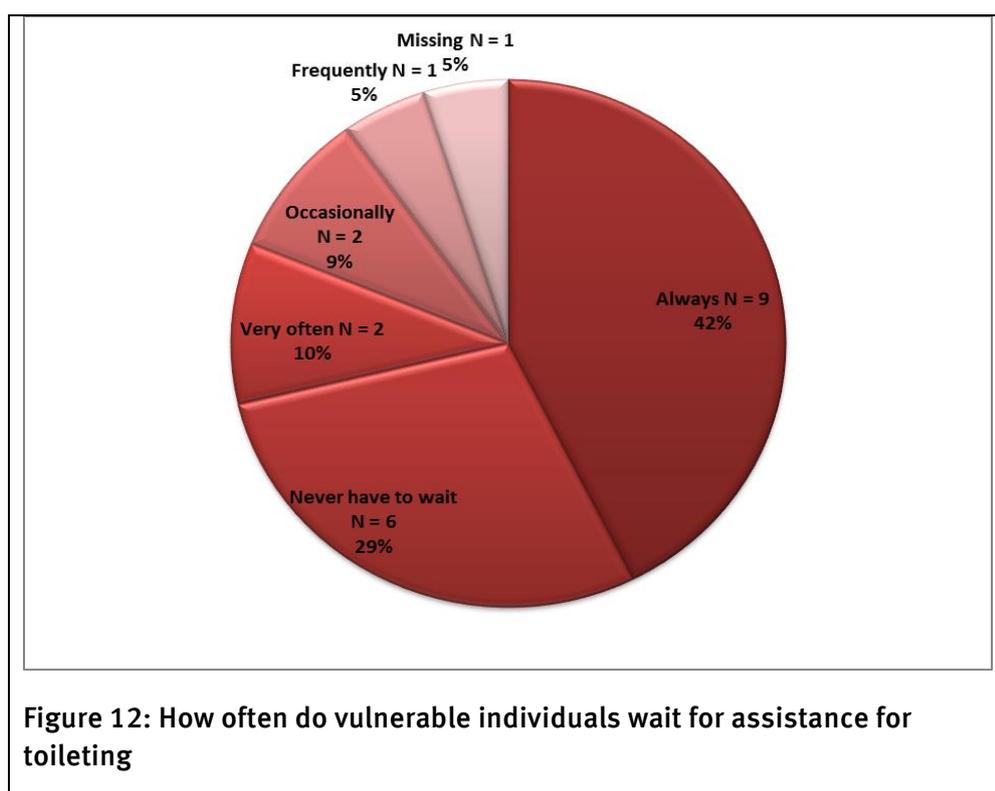
Lack of safety was also raised by almost half of respondents (44.5%). Safety concerns included possible sexual assault in the bush. Both vulnerable and non-vulnerable women expressing a concern about being at risk of rape while practicing open defecation, particularly at night or if they needed to venture far into the bush for privacy (17%). Girls and women who are disabled are already at increased risk of sexual abuse and violence because they are viewed as more physically vulnerable and as less likely to be believed if they try to report such violence.<sup>21</sup> 27% of respondents said they fear being attacked by wild animals, especially snakes. For example, one frail older woman with very poor vision reported that the week before she had put her hand down on the ground to support herself, directly on top of a snake.

### 3.4.4 Need for assistance

16% (n=21) of vulnerable individuals interviewed stated they need help with toileting, which could include assistance reaching the toilet, either in the household or bush. In some cases, it included help in undressing, positioning and balancing to relieve themselves.

Generally support was provided by adult women (52%) and older girls (62%). The remainder who need help received assistance from several household members – a task still largely provided by women. Boys and adult men were reported to help only when nobody else was available.

Of those people who needed assistance using the toilet, 29% (n=6) said they never need to wait, because there is always someone nearby available to help. 28% reported that they ‘sometimes have to wait for assistance’. However, 43% (n=9) reported they always need to wait for someone to help them (Figure 12). The need to wait for assistance is a substantial issue and one raised regularly by disability advocates and advocates for older people.



Individuals who need help using the toilet reported adapting their behaviour to place less strain on their caregivers. Although numbers needing assistance with toileting are small (n=21), of those who needed assistance 19% reported they try to go to the toilet less frequently than they actually need to. This is because either there is no one home to help them or they do not want to overtax their caregivers. 14% report routinely

refraining from eating or drinking as much as they want so as to reduce the number of times they need to ask for help to relieve themselves. Several informants reported trying to reduce use of the latrine by planning ahead (e.g. asking to be taken before everybody leaves the house, using a chamber pot), or by delaying eating and drinking until late in the day when family members have returned home and can help.

In focus groups and interviews many people also reported regularly adapting their behaviours, especially if things were busy around the household, guests were expected or they planned to travel beyond their homestead that day.

The health implications of this routine delay or denial of food and drink is of concern. In a very hot climate, dehydration, particularly among vulnerable individuals, has significant adverse health implications. For chronically ill or disabled individuals, for whom getting enough calories and a balanced diet is already an issue, skipping meals or under-eating until later in the day, is of equal concern.

29% of those who needed assistance report occasionally soiling themselves while waiting for assistance, meaning loss of dignity to themselves and additional work for caregivers.

### 3.4.5 Adaptations of toilets

All heads of household, of those both with and without vulnerable members, were asked whether any adaptation had been made to toilets to help household members reach and use the toilet more easily.

In households with no vulnerable members, 94% of all household heads stated that no changes had been made. There was not strong interest in making such adaptations where the need did not exist.

The picture was somewhat different in households with vulnerable members. In most such households (64%), no adaptation had been made. However, 36% of household heads (n=45) reported that some adaptation had been made to try to make it easier for the vulnerable individual to get to and from the toilet (with or without assistance).

Of the 45 household heads reporting adaptations, the changes made were generally minor, relating to path improvement (61.5%) and moving the toilet nearer to the house (42%). Use of ropes, raised seats and ramps was mentioned by a handful of other household heads, but these types of low-cost, low-tech adaptations were quite rare. In a few households more than one type of adaptation had been tried. Notably, low-cost adaptations such as grab bars, handrails, or rope guides were rarely mentioned.

Of the 45 respondents who had made adaptations, almost all reported being pleased with the results, most stating that they believed all members of their household benefited from improvement in terms of cleanliness, dignity and accessibility. 8% specifically commented on how the new arrangement also saved time and energy for the caregiver.

Interestingly, when vulnerable individuals were asked about adaptations to improve accessibility, many were less enthusiastic about the improvement. Only 13% (n=17) of the 128 vulnerable individuals who responded to this question stated that some adaptation had been made, compared with 36% of heads of household. This might reflect the fact that many changes reported were not explicitly done to improve accessibility for vulnerable household members (or to improve accessibility alone). Reflecting on the responses given by household heads, vulnerable individuals who were surveyed reported that adaptations included path improvement (18%) and moving the toilet nearer to the home (41%). In areas in which adaptations had been made, 47% of the vulnerable individuals said they were not consulted before adaptations were implemented – this is considered to be a major institutional barrier.

#### 3.4.6 Cost as a factor

In households where adaptations had been made, household heads were asked to estimate how much the changes had cost. Responses about the length of time and costs of such adaptations varied considerably. Household heads who had made adaptations reported taking between 18 hours and one month, and cost estimates varied widely. This appears to be because most building projects at the household level are done over a long period, when families have the time and can afford the materials.

Tool 8 asked household heads about construction costs for a new latrine. Again, there were a range of responses. Cost in terms of time requirements ranged from two to 30 days, with 14 out of 20 cases (70%) estimating that construction time was a week or less. This appears to reflect whether the householder was able to devote a concerted period of time to construction or whether work on the latrine was done between other chores and household duties. Additionally, time needed to collect materials (varying from one day to two weeks) was also included.

The cost of the latrine included time needed to collect materials, use of materials manufactured outside the local area (iron sheets, nails, cement, reinforcement wire) and materials bought locally (sand, stones, thatch poles, clay, grass and thatch). Only in two cases could the household head estimate the actual cost of construction (630 kwacha; 800 kwacha).<sup>22</sup> Cost of labour was not recorded because of the difficulties of attaching a 'wage' amount to a person's time and the challenges of estimating the amount of time devoted to household activities when time permits over the course of days or weeks.

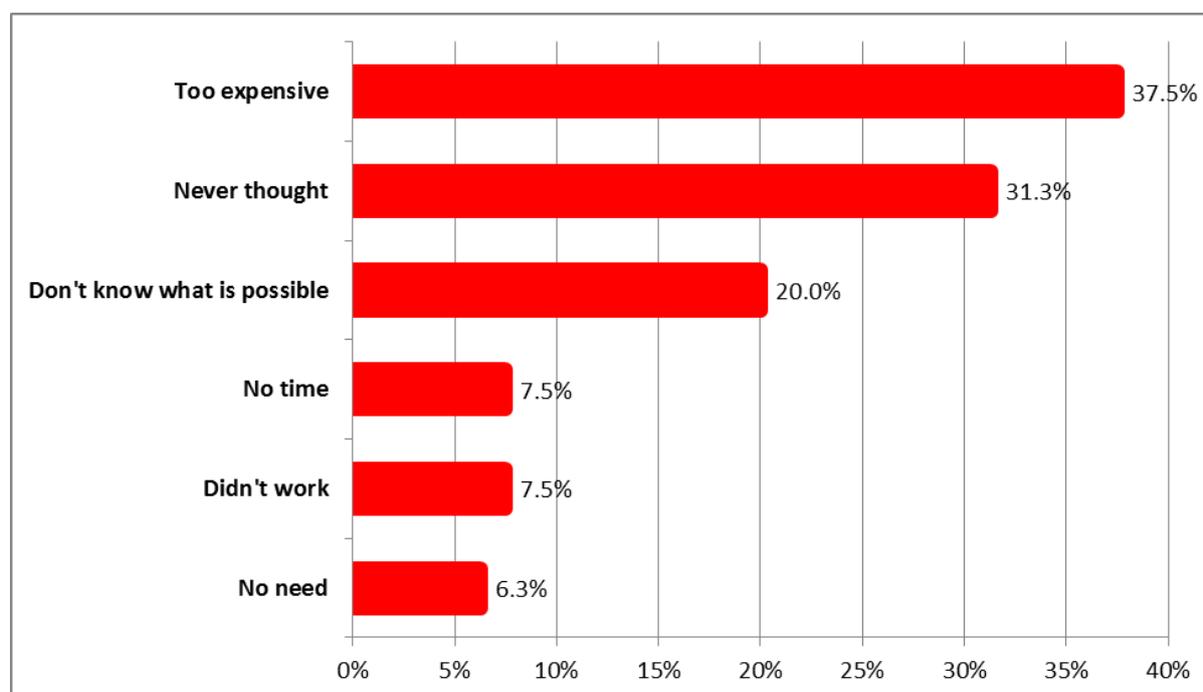
The cost of maintenance was even less clear for many householders; five (25%) responded "don't know" when asked about how much latrines cost to maintain.

Several vulnerable informants reported that church groups (Adventists and Catholics) dug a toilet for them, or they had heard about someone for whom such a toilet was built. Such adaptations were not commonly reported. "They help us," said one older man, "but in a small way."

### 3.4.7 Knowledge and information about latrine adaptations

Importantly, in households with vulnerable members, 51% of household heads reported that they have made no adaptations because they had ‘never thought about it’, or ‘didn’t know it was possible.’ Knowledge was also poor among vulnerable individuals themselves – 19.5% of vulnerable respondents stated that ‘nothing could be done’, apparently reflecting their lack of knowledge about the possibilities of adaptations to improve accessibility. In interviews and focus groups many household heads and vulnerable individuals also assumed that only major adaptations (e.g., building new latrines) would solve environmental barriers.

37.5% of the household heads who had made no changes reported that they had considered making adaptations, but, envisioning the need to build or rebuild the family latrine, felt it would be too expensive. Another 7.5% said they did not have the time for such major construction (Figure 13).



**Figure 13: Reasons given by heads of household for not making adaptations to latrines**

60% of vulnerable respondents thought that their family would be inclined to make some changes if minor, inexpensive adaptations, were available. Another 19.5% were not sure whether or not their families would be willing. Only 8% said that their families definitively would not consider a change. Of vulnerable individuals interviewed, 75% could give no estimate of what minor or major adaptations would cost or how much time would be needed to make such adaptations.

It is important to note that when vulnerable members were asked about the type of changes that would potentially help them to meet their toileting needs most referred to

simple additions, such as something to hold on to or balance themselves more easily when they needed to squat or bend (46%). Only 9% of vulnerable individuals volunteered substantial changes, which primarily meant building new toilets or building them closer to the house. Another 14% simply stated that ‘anything would be better than the current arrangement’. One older woman said “the one I use scares me because I fear I might fall (in).”

Significantly, after household heads and vulnerable individuals were surveyed or interviewed, several asked for information about improving accessibility. They requested pictures, designs, photos and information on how simple adaptations could be made. Several informants surveyed also suggested that ‘trying out a real example’ would be helpful, although, for most, a photo or instructions for building their own latrine was the top priority. The possibility of being able to see photos or instructions via cell phone or in a booklet was raised by several informants.

A lack of knowledge of options, especially low-cost changes that could easily be made to existing facilities, or information on the potential costs involved, proved to be a sufficient barrier for household heads. Comparable lack of information on possible adaptations or costs also proved a barrier for vulnerable individuals because it limited their ability to suggest changes, or to ask their households to spend money on such changes.

This lack of information was also found among focus group participants, most of whom did not know that toilets could be adapted for people who have difficulty walking or squatting. In one focus group, an older man, aware that such adaptations were available, reported that he had heard of an adapted toilet at the school for children with disabilities in Nanga town:

“What they do is they make a small hole and on either side, they put bricks then a child sits on top...But I have never seen it.”

In another focus group an older man with physical disabilities had tried an adapted toilet when in an urban area, and described its strengths and weaknesses to the assembled group:

“So there is a problem there. Where to hold? There is nowhere to hold. But sitting, I saw it OK, because even me, am disabled, I sat nicely without difficulty. But just to stand (up), for you to stand (up), that’s where there is a problem for you to hold.”

In focus group discussions with vulnerable individuals, although there was substantial interest in the possibility of adaptations, most participants considered such adaptations unlikely to be used in their rural communities. As one respondent noted:

“OK, the toilets that have a pot like thing. If they are there, I think they are still few. Yah, we haven’t learnt them. The thing we learnt is the hole that when you squat and the dirty drop into. If we learn that there are disabled people who

cannot manage to squat, I think we can appreciate. Us, we think that those toilets with pots for sitting on are town toilets.”

Two people also mentioned an adaptation made for individuals who could not squat: an inexpensive plastic chair with the central part of the seat cut out, positioned over the toilet hole to allow the individual to sit instead of squat.

In other focus groups, many participants thought that making accessible toilets would be a considerable undertaking;

“I think every person can afford to have a toilet. Just finding time to sensitise takes long time, so that modern toilets should give us, but to have tools for some to build a toilet that can last for over ten years is difficult – like cement and iron sheets.”

## 3.5 Access to hygiene

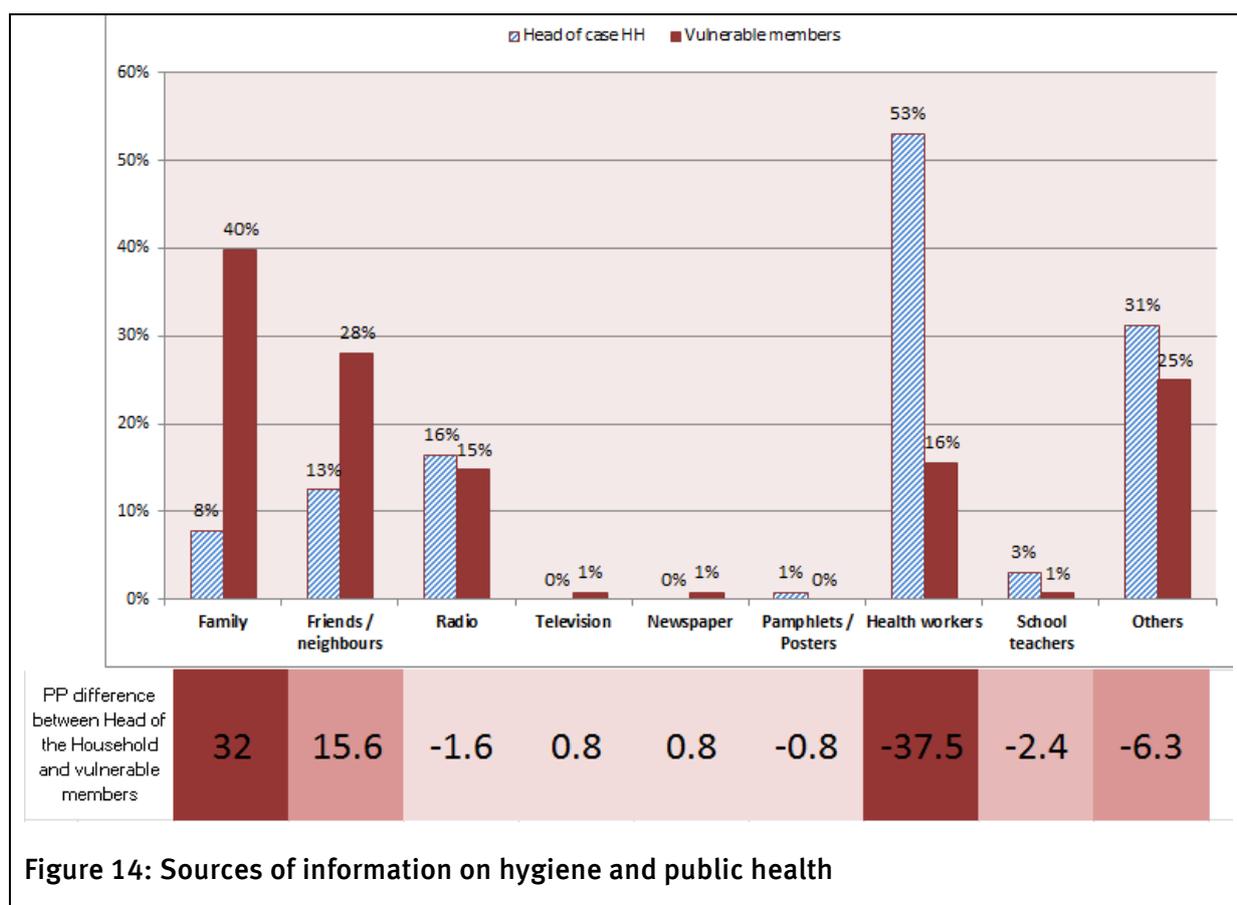
### 3.5.1 Sources of information

Several questions in Tools 1 and 2 and in focus group discussions sought to identify how members of the local community received information related to hygiene and public health.<sup>23</sup> The rationale for this was to understand how current public health information might circulate within the community and to identify how information on making WASH services inclusive and accessible might best reach the proposed recipients.

Within the communities surveyed, household heads reported that the most important sources for hygiene information are health workers (53%). Radio was next (16%), followed by family and friends (12%) and a broad category of “others”, which includes religious organisations, NGOs, and community groups (31%).

Interestingly, vulnerable individuals themselves reported a different pattern of sources of information about hygiene and public health. Within this group, whose members have lower levels of education and literacy and who are more likely to stay in the home or around the homestead, there was a greater reliance on information from family members (40% versus 8%) or friends and neighbours (28% versus 12.5%).

Health workers played a far smaller role (16% versus 53% for household heads) and school teachers were a negligible source of information (0.7%), although they are not a significant source of information among household heads either (3%). The reach of radio was about equal for household heads and vulnerable individuals, although individuals with hearing loss or deafness are not reached by radio. A quarter of vulnerable adults (25% versus 31%) reported that ‘other’ groups such as religious organisations, NGOs and community groups were also a regular source of information.



The finding that vulnerable individuals are more reliant on social networks (friends and family) for information on hygiene and public health is an important one. To reach this group with public-health messages and information about inclusive and accessible WASH designs, campaigns must be targeted to these individuals. Public health messages designed to reach households should also be designed to be discussed within the household. (i.e., include the suggestion to talk this over with everyone who lives in your household).

### 3.5.2 Anal cleansing

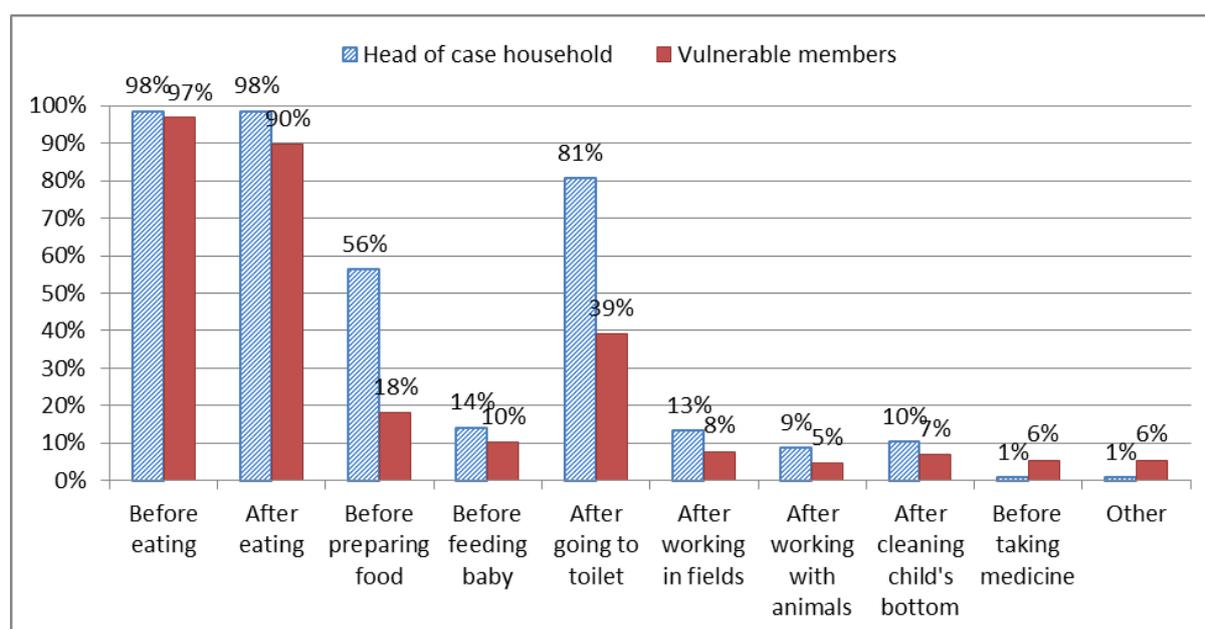
Anal cleaning materials used included paper, leaves, and other materials. Those individuals who used the household latrine reported using paper when it was available, however generally paper is not available and individuals used leaves and whatever other materials were at hand. Those who practised open defecation used whatever materials were at hand; sometimes they had nothing to use.<sup>24</sup>

Data from the Latrine Observation Checklist (Tool 8) showed that in 15 out of 20 latrines surveyed (75%), no anal cleansing materials were observed. According to householders, in 19 out of 20 household latrines (95%) anal cleansing materials are normally dropped in the pit, as were sanitary pads. In one case there was a receptacle inside the cubicle.

### 3.5.3 Handwashing

Household heads reported that they and members of their families regularly wash their hands after going to the toilet (81%), whereas only 39% of vulnerable household members reported being able to do so. Data from Tool 8 however do not bear this out. Availability of handwashing facilities was much lower than would be expected from reported use. A handwashing facility with water, soap or ash showed signs of recent use in only three of the 20 latrines surveyed (15%) and only two (10%) were available within 5m of the latrine.

The number of respondents who report washing their hands before eating was high – almost equal between household heads (99%) and vulnerable individuals (97%). The practice of handwashing after eating was comparable, although lower among vulnerable members (98% versus 90%). This might reflect the fact that when the family gathers for a meal someone is available to help the vulnerable individual reach and use water to wash their hands. Figure 15 represents a comparison between responses from the vulnerable individual, and the head of the household with a vulnerable member.



**Figure 15: Handwashing practices: head of case household/vulnerable member**

A lack of access to soap and water, especially among vulnerable individuals who do not use household latrines or who cannot reach or pour water after defecating might explain this discrepancy. In interviews and focus groups, vulnerable individuals were very clear that washing hands after using the toilet was preferable, but not common.

Regular handwashing was less consistent when vulnerable people carried out household chores (such as food preparation, childcare and working in fields or with livestock) where it might be difficult for individuals with mobility problems to easily

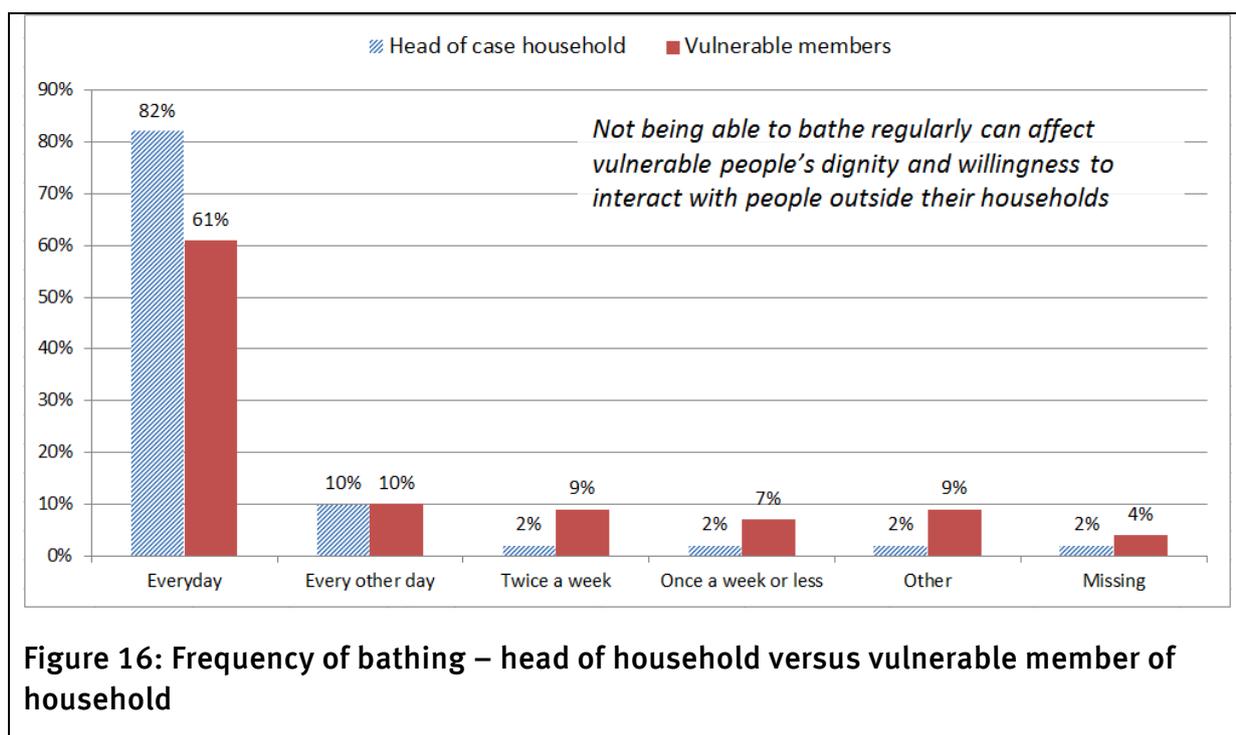
access water. Furthermore, they do not want to bother others to help them access this water for handwashing.

Soap is expensive and only 21% of all heads of households and similar numbers of vulnerable individuals reported using soap and water, with the rest using just water (78%). 1% used ash and water.

### 3.5.4 Bathing

86% of all household heads report that they bathe daily and another 9% said they bathe every other day. Only two said they bath less regularly, defined as twice a week or less. In line with these findings, 95% stated they can wash themselves as often as they would like and only 5% said they were unable to do so.

The pattern for vulnerable respondents was distinctly different. Only 61% bathe every day and 10% bathe every other day. The remaining 26% were unable to bathe on a ‘regular basis’. The percentage of vulnerable people satisfied with the frequency of bathing reflected this division, with 25% feeling that they were unable to bathe as often as they would like (Figure 16).



20% of vulnerable respondents stated that lack of ability to bathe regularly makes it difficult for them keep clean. In communities where regular bathing is the norm, the inability of some vulnerable individuals to bathe regularly has implications for their dignity and ability to feel that they can interact with people outside their households or in public.

The inability to bathe regularly can also have serious health implications. Many individuals, especially those with physical disabilities including older adults and those with chronic illnesses who sit or lie in one position for long periods, are at risk of pressure sores and abrasions. Such sores and abrasions can easily become infected unless they are kept very clean. The need to keep clean to avoid infections is also vital for those who have chronic illness such as HIV or AIDS – pressure sores, open wounds and diarrhoea increase the risk of infection in people with already compromised immune systems. Such infections can have serious or deadly consequences, especially in poorer households where clinical care and antibiotics might be hard to come by.

Bathing is usually done in a closed room (75%) or outside in the yard (16%). Privacy, defined by those interviewed as being able to bathe without being seen by others, is important. 81% of vulnerable individuals interviewed were generally satisfied with the privacy afforded to them and feel that their privacy is protected. However, 19% were not satisfied and reported being bathed in an area where privacy was lacking. “Anyone would see me naked,” said one, either because a fence or wall is falling down, or because there is no area in their homesteads where their caregivers can, or chooses to, bathe them in private.

In surveys, focus groups and interviews, 80% of vulnerable individuals consistently said they did not want to overtax caregivers. This reflects responses detailed in section 4.4.1, where 25% of vulnerable respondents reported that they cannot carry water or enough water to bathe regularly. Another 21% reported they did not want to bother other people to carry water for them. 69% of those vulnerable individuals interviewed reported that they needed help bathing themselves, and 34% reported a combination of these issues under the broad category of ‘needing help’. These informants noted, as in other components of this study, that they did not want to overuse the support system available to them.

The barriers to vulnerable individuals for bathing are interpreted by household heads, vulnerable individuals and caregivers as a reflection of the individual’s physical limitation, rather than being a result of potentially changeable environmental and attitudinal barriers.

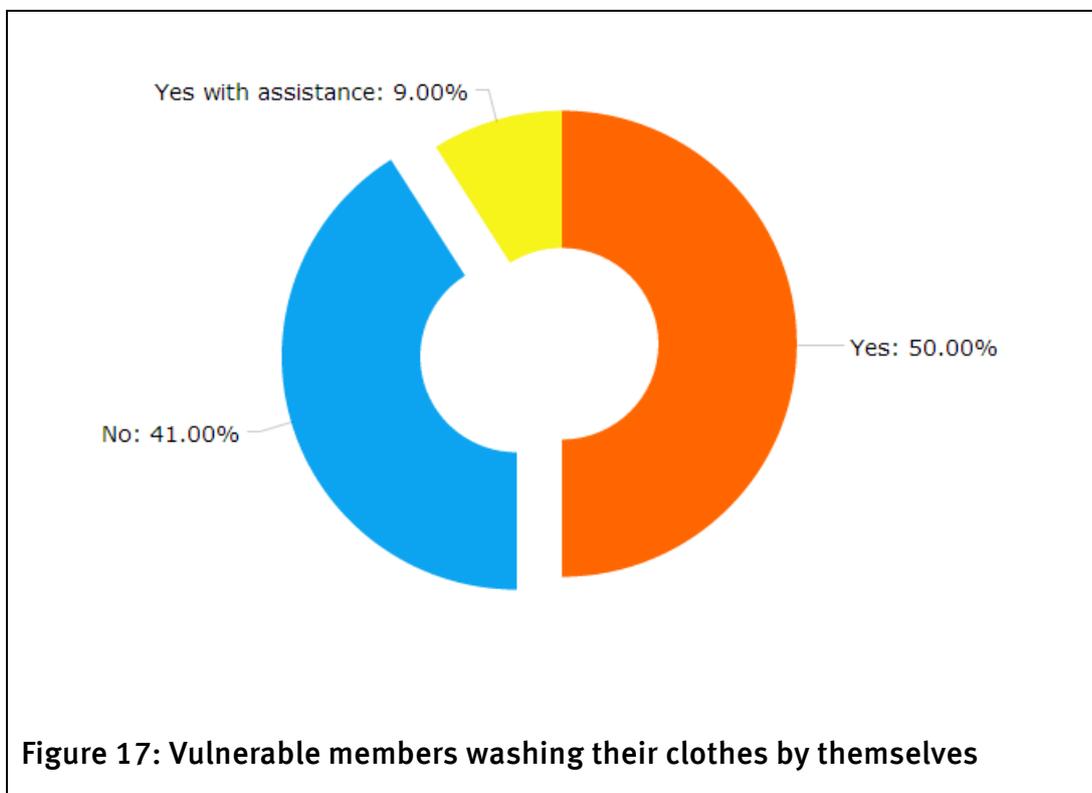
Assistance with bathing was mainly provided by adult women and girls (77.5%). When men and boys were identified as helping with bathing, this largely entailed carrying water. Where ‘helping’ involved additional activities, such as assistance with undressing and dressing or helping with scrubbing and drying, this was largely left to the female members of the household. In 11% of households, men took primary responsibility for bathing – this was generally the case for older men with older wives.

Again, the overwhelming number of women compared with men primarily responsible for helping vulnerable individuals bathe adds a gender dimension to these issues. Given the host of chores adult women are already responsible for, lack of easily accessible bathing options for vulnerable individuals adds an additional chore for women whose time is already overstretched.

### 3.5.5 Washing clothes

Finally, vulnerable individuals were asked whether they washed their own clothing or relied on another member of the household to do so. In the Mwanza West Ward, washing clothes is done by women for all members of the household. 76% of household heads reported that the mother of the household was usually responsible for washing clothes, with grandmothers, adult daughters and girls filling in for most of the rest of this chore or assisting the mother in doing the laundry. In only 10% of households, respondents reported that ‘everyone’ is responsible for washing clothes, or that fathers did the washing.

However, vulnerable individuals, and, in particular, vulnerable women, reported that they washed at least some clothing themselves (50%). Another 9% did so ‘with some assistance’ on a regular basis (Figure 17).



According to information gathered in focus groups and in-depth interviews, the additional amount of washing done by vulnerable individuals reflects the fact that many spent long periods sitting or dragging themselves across dirty surfaces, such as toilet floors and open defecation sites. Rather than burden others with their laundry, or because they had few clothes, they wash their own clothes.

### 3.6 Amount of water used

Both household heads and vulnerable individuals were asked whether vulnerable individuals use the same amounts of water as other household members. Household heads reported that vulnerable individuals use the same amount of water. Several vulnerable household members reported that they regularly try to use less water so they are not a burden to their households. This reflects the findings in the sections on access to drinking water, sanitation facilities and water for bathing.

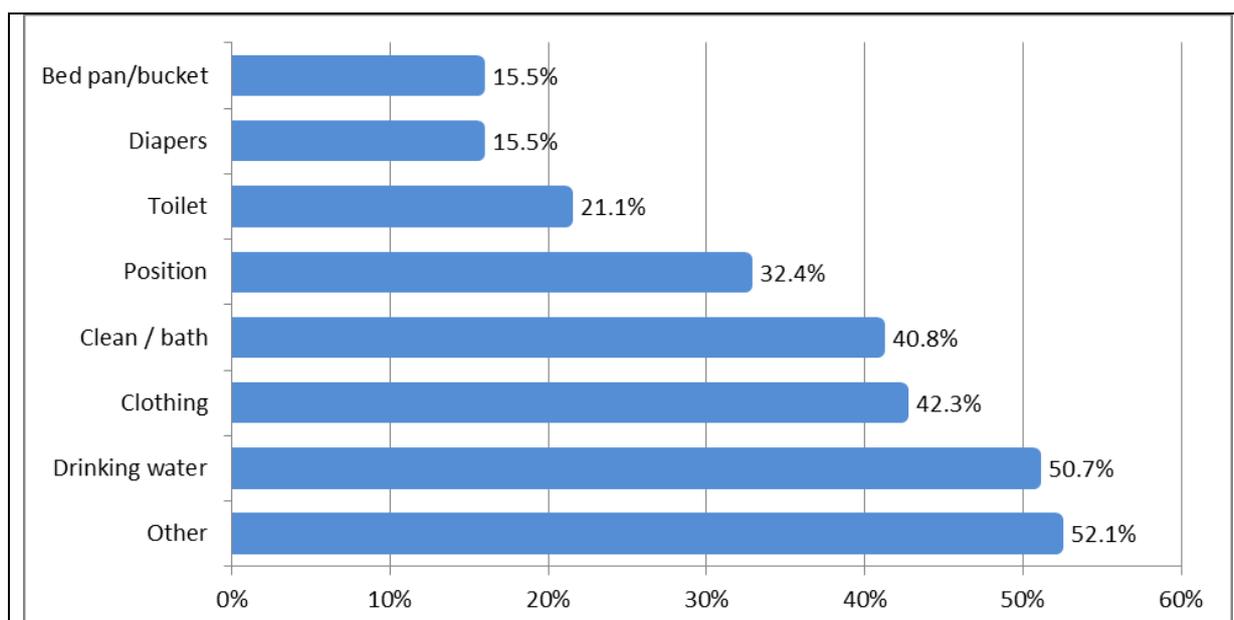
Vulnerable individuals were also asked if their need for water had changed over time, and why this might be the case. The results here were mixed: 53% reported their needs had remained the same over time; 36% reported using less water, in part because they were less active; and 20% reported a conscious effort to restrict their water usage if they cannot help fetch water themselves. 6% reported using more water because of medical needs, to wash regularly or to clean themselves and wash their clothing more because they had to drag themselves across dirty surfaces.

### 3.7 Caregivers

The presence of a vulnerable individual in a household has implications for everyone in the household. In this study, we were interested in understanding the amount of support and assistance needed by vulnerable individuals related to WASH activities, who was supplying such support and what other activities might be forgone when time and energy was given to such assistance. After our initial round of data collection (Tools 1–9) a supplementary set of four focus groups were held, in which information was collected from individuals who identified themselves as ‘primary caregivers’ (n=71). The caregivers are family members on whom the disabled, chronically ill or older people rely for assistance throughout much or all of the day.

Of these 71 primary caregivers, 73% stated that they always help provide support and assistance to the vulnerable member of the household, 15.5% stated that they do so sometimes, and 11% reported that they did so occasionally.

The most important finding from this set of focus groups was that a substantial amount of all the assistance caregivers provide involves WASH-related activities, such as fetching water, bringing drinking water to vulnerable individuals, helping vulnerable individuals reach and use the toilet, helping them bathe and washing their clothes (Figure 17). Other vital daily activities included helping the vulnerable household member dress, cooking for them and in some cases helping to feed them. Only two women mentioned being responsible for administering medication or taking vulnerable members to a hospital or clinic for health care. These activities were done in addition to the regular set of household chores expected of all women: cooking, cleaning, child care, gathering firewood and working in the fields (Figure 18).



**Figure 17: Caregiver support and assistance in WASH activities**

73% of caregivers reported they are involved in providing support and assistance ‘many times’ or ‘all the time’ during the day (Table 7).

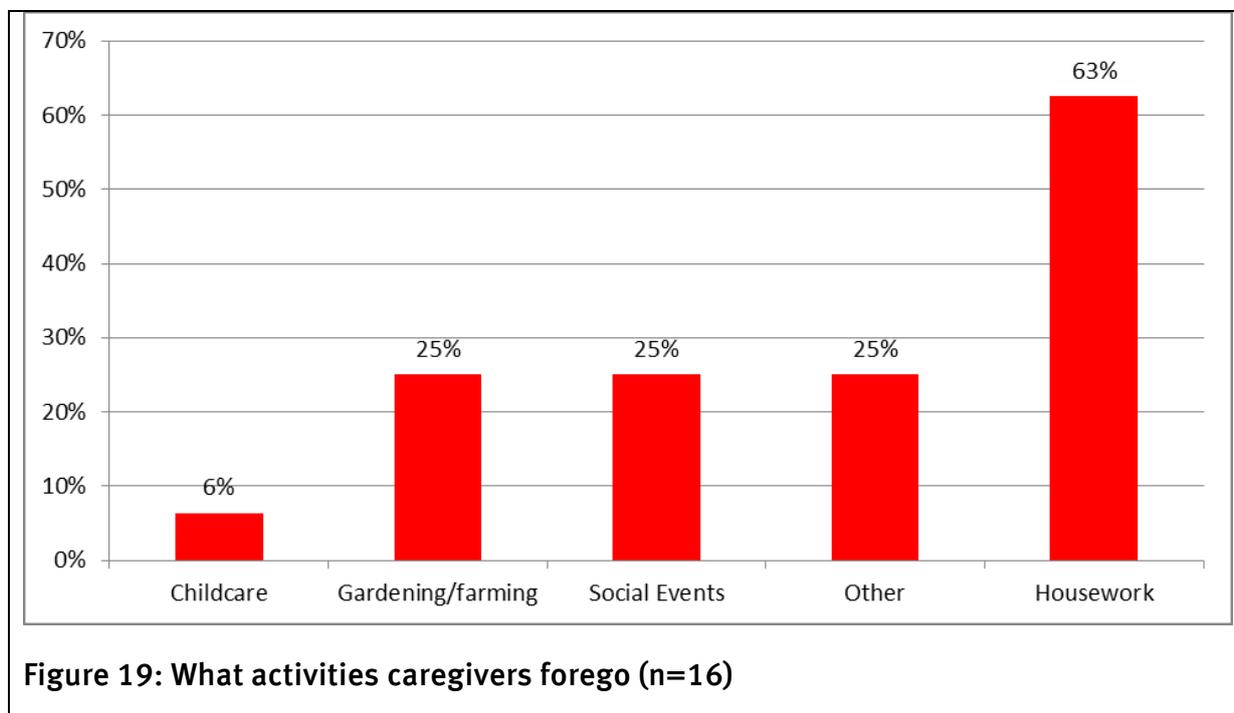
Table 8: Frequency of support and assistance provided by caregivers		
Daily pattern of support and assistance	N	%
Once daily	10	14
2–3 times	8	11
Many times	33	47
All the time	19	27
Missing	1	1
Total	71	100

41% said that they plan their daily schedule around the needs of their vulnerable household member. When asked to specify how their caring duties affect their own schedules and how they included these activities into their daily routines, the caregivers specified a range of strategies. For many, providing support and assistance was ‘part of the daily chores’. Other respondents were more specific:

*“I clean and feed her in the morning, go to the field then check on her four times before knocking off.”*

Whereas 41% (n=29) planned their daily schedule around their vulnerable family member, only 22.5% (n=16) report that the time given to helping the vulnerable individual keeps them from doing other activities or other chores.

Those who think that caring activities prevent them from other activities were asked to specify which activities they would do otherwise (Figure 19).



Comparable information was collected from vulnerable individuals. Although the number who responded to this question was small, of the 16 vulnerable individuals who answered the question ‘Who stays at home with you?’, 87.5% (n=14) reported that it was an adult female (mother, aunt, grandmother). One husband was reported as being the primary caregiver to his frail older wife and one person stated that she is helped by anyone who is home at the time. 24% of all individuals who needed assistance reported that ‘no one’ stayed home solely or primarily to help them.

48% of vulnerable individuals reported that the primary caregiver stays home ‘all of the time’ and 39% reported that the pattern varied from day to day, but the primary caregiver ‘comes home to help’ or ‘comes home from the fields’ throughout the day.

Vulnerable individuals were less specific than the primary caregivers about the activities that their caregivers took time away from to provide support and assistance, but most believed their caregiver took time away from other significant economic or family responsibilities. 29% specifically stated that their primary caregiver would probably ‘stay at work’ or ‘in the fields longer’, and another 14% reported that the primary caregiver would do ‘more chores at home.’ One answered that her caregiver would ‘spend more time with children.’

Primary caregivers were identified most frequently as being adult women. Only two vulnerable individuals answered that if their primary caregiver was not providing care, that she would ‘attend school more often’. This might indicate that, although the

primary caregiver was consistently identified as an adult woman, in several households, older girls might share some of the responsibility and, when needed, stay home from school to help.

### 3.8 Lack of WASH services in public spaces

Inquiry was also made into the availability of accessible toilet facilities in public places (markets, churches, schools and health clinics) and how lack of such facilities might limit the choices people make in travelling outside the home. However, not all vulnerable individuals have equal problems with accessing toilets. This is a concern specifically for those with physical impairments and vision problems, and is of far less concern for people who have limitations related to hearing, intellectual ability or mental health concerns. For those who have such limitations, difficulties in finding a toilet in a public space significantly restricts their movement beyond the household.

69% of vulnerable individuals said that finding a toilet was not a problem, 13% of all vulnerable respondents reported that they had trouble finding an accessible toilet in the community, and another 17% stated that they were unable to leave the house because they were not mobile. 58% of respondents (n=17) who reported having trouble accessing toilets at home because of mobility problems or other limitations reported also having to limit travel outside their homesteads because of a lack of accessible toilets in public spaces.

Several disabled people interviewed reported that although they could use public facilities they often found themselves the centre of attention from young people who would tease and jeer when they went to use a public toilet. In one focus group a young disabled man said:

“I was in Kafue and they refused me to enter a toilet...I have started being...embarrassed just because of my disability.”

A middle-aged man who uses crutches noted:

“It happened at a certain school. Quite big children started laughing at me. Asking them to say ‘why are you laughing’; they say ‘why are you not standing upright. I just kept quiet and tears dropped.”

A middle-aged woman noted that the lack of public toilets is a major barrier to her participation in the broader community. She explained:

“I don’t feel comfortable in mixing with people. I feel troubled. I prefer staying at my home alone. I have a big problem.”

Such behaviour was not reported in all communities surveyed, but neither was it unknown.

An especially disturbing anecdote was provided by one disability advocate who was sent to a meeting of local NGO groups working on development issues for the first time. Because there was no accessible toilet, he soiled himself during the meeting and was too embarrassed to return and participate in future meetings. A lack of an accessible latrine means that development plans in his area are moving forward without the participation of an effective representative from the disability community.

### 3.9 Schools and WASH facilities

Drawing on data from tool 6 (interviews with teachers and observational checklists of school WASH), it appears that, for the teachers, accessibility simply refers to ramps. Accessibility for children with other types of disabilities, such as visual impairments or intellectual disabilities, were not issues they had considered.

All five schools stated that their classrooms were accessible to everyone. However, only one school had actually made adaptations in which a ramp had been constructed into the main school building.

Teachers in all the schools reported that all children in their schools used the same water sources and toilets. In no school was there a separate accessible toilet. Distance from the classrooms to the toilets varied. In one school, it was only 10m, but in three of the schools the distance was between 30m and 100m.<sup>25</sup> One school reported the distance was 'more than' 100m but did not specify further. Teachers did not feel that there were major environmental barriers to the toilet, but the observational check list found that in two of the five schools path surface, slipperiness or steepness were issues, as were cleanliness, smell and flies. None had steps that blocked entrance into the toilet itself.

Privacy was less of a concern, with none of the toilets users visible from outside. Two toilets had lockable doors and three did not. Light was also an issue in the toilets observed. One school toilet had 'plenty of light' in the toilet, but in another two schools this was a problem. This is a particular barrier for people with a visual impairment or for menstruating girls who need light to change their soiled cloths or pads. In four schools no anal cleansing materials were observed. However, in three schools teachers reported that children brought their own paper with them. In all schools, toilet paper and sanitary napkins were dropped directly in the pit. One school had soap available and it was located less than 1m from the floor, making it accessible for shorter students or those using mobility aids. In the other four schools, soap or ash was unavailable.

Teachers also reported that children with disabilities attending their schools were able to use the toilets independently. In one school, when asked about accessing the cubicle for children with crutches, the teacher reported "yes, there is plenty of room". In another school, the teacher reported it was possible to enter the cubicle, but that there was difficulty "in shutting the door". The rest did not comment.

It is also of note that there were relatively few students with physical disabilities recorded in the survey, so the lack of accessibility issues raised might be less a reflection of improved accessibility, and more about the few children with physical disabilities at school. This highlights additional environmental barriers for children with disabilities in getting to school, such as lack of transport.

None of the teachers reported that disabled children in their schools needed help to use the toilets, nor were there any reports of parents needing to come to school to help their child use the toilet.

Where environmental barriers exist it is also possible that children who find the school toilets inaccessible will be less likely to attend school in the first place. When teachers were questioned about this, two of the five said that this might affect attendance rates, but all felt that such attendance rates might be a more complex issue. When asked about the attitudes of other students, there were few extensive comments but all teachers felt that disabled students were at risk of being teased or bullied. A significant problem raised for all children was the limited number of toilets available in relation to the size of the student population and the rush to get to toilets and back from toilets during break time. In such situations, children with disabilities – some of whom might be slower to get to and from the toilet, are less able to wait without having an ‘accident’ and soiling themselves. This puts them at a competitive disadvantage. When they are slower or have an accident, this can only compound the teasing and social isolation.

As one teacher stated:

“They feel shy because the facility does not suit.”

Another teacher volunteered the fact that lack of accessible toilet facilities makes it more difficult for children with disabilities to learn while they are in school:

“They cannot concentrate in class because when they are learning, they are thinking of how to use the toilet.”

Another stated that lack of accessible toilet facilities are a distraction for children with disabilities because “they worry about what other children will say.” Another teacher stated:

“Some disabled boys and girls in the community cannot attend school because the toilets and classrooms are not user-friendly. We also have no teacher who did special education.”

Another teacher who also thought that attendance of children with disabilities was limited by a lack of accessible toilets reported:

“The government should consider building more toilets and classrooms favourable for the differently abled.”

It should be noted that there are efforts in the area to improve school toilets, with funding from the District Planning Authority for adequate toilets in a series of local villages. However, it is unclear whether these new latrines will be more accessible than the ones already available.

### 3.10 Attitudes towards vulnerable people

One final group of findings should be noted. A substantial amount of research indicates that traditional stigma and prejudice towards vulnerable individuals, particularly people with disabilities, limits their social and economic inclusion in many communities.<sup>26</sup> Therefore, questions about attitudes towards vulnerable individuals were asked in both qualitative and quantitative data-collection tools.

A range of attitudes were reported. Many community leaders and members of the general public had progressive ideas about people with disabilities and many strongly expressed the belief that everyone should be treated equally. A number of people reported that there had been a change in attitude, as modern media and disability rights campaigns begin to introduce new ideas and understandings. However, some household heads, community members and community leaders and many people with disabilities reported regularly encountering traditional negative beliefs. Figure 6 captures key words used by vulnerable people in focus group discussions to explain the attitudes of non-vulnerable people.

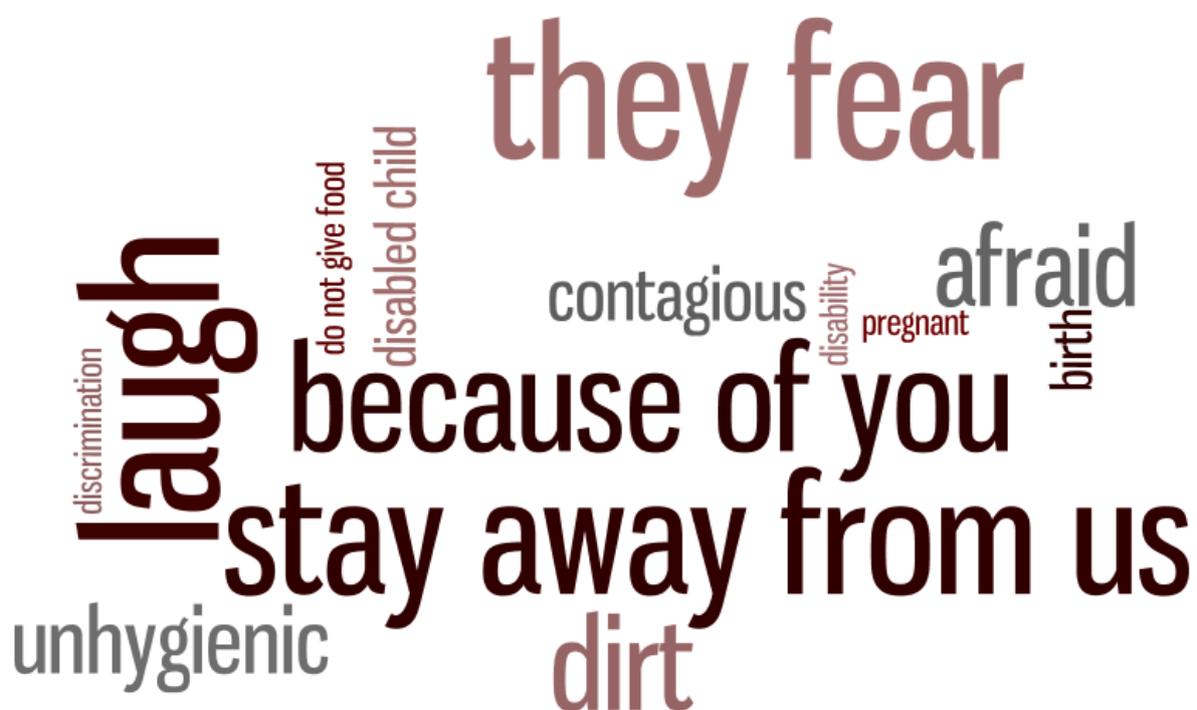


Figure 6: Key words from focus group discussions with vulnerable individuals

In one focus group, a middle aged man who described himself as ‘lame’ noted:

“They laugh. If you pass by, you find that they laugh. ‘Look at the disability that that one has.’ So many laugh. They don’t see this as a God-given condition.”

The beliefs that disability is contagious or that interaction with people with disabilities can cause a mother to give birth to a disabled child were reported in focus groups and in interviews with enough frequency to indicate that this belief continues to be held by some members of the community. As one physically disabled man explained:

“They fear walking with us because of the disability we have. Some women who are pregnant think that ‘I will give birth to a disabled child like that one.’ They fear, (and so) they stay away from (us) because of the disability we have.”

Indeed, in one focus group with several vulnerable individuals, there was discussion about a court case:

“The issue even reached the court. There is a woman who was pregnant who passed there...then the husband (of) the (pregnant) woman came to the mother of this (disabled) girl, beating her, saying ‘my wife has given birth to a baby with a hump because of you.’”

Others reported that people with disabilities are routinely seen as dirty. One woman with a disability mentioned that she avoided socialising regularly with people other than immediate members of her family:

“There are times when we go to visit; others do not give you food because they think you will leave dirt. So sometimes we are afraid to visit.”

One head of a household with no vulnerable members explained that he feels that disabled people are unable to squat over a pit latrine, so are more likely to soil the toilet.

“Even going to the toilet, if [people] see a disabled person has entered in there, they won’t enter because they know that...they will not sit like everyone else does. They find it unhygienic. There is discrimination because they think that disability is a disease, is contagious.”

Many members of the community also described low expectations of people with disabilities. One mother of a disabled daughter said:

“Many get surprised how I manage. (They) ask ‘how do you manage to care for that one which you take care of....They get surprised. They think even food, maybe there is a particular, different food than the food we eat. But we eat the same food and I try hard to ensure that the disabled (daughter) eats better food.”

People with chronic illnesses such as HIV or AIDS and TB reported similar discriminatory attitudes – fear of contagion and the assumption that they were unclean. These negative beliefs can lead to social isolation because some members of the community hesitate to interact with vulnerable individuals. Vulnerable individuals themselves often limit their interaction with those outside their household in fear that they will be poorly treated. This might also limit the willingness of some households to devote time and resources to inclusive WASH efforts. This assumption will be tested in the mid-term review and evaluation.

### 3.11 Interviews with community leaders

Tool 5 collected responses from six local community leaders (senior headmen, headmen and community leaders)<sup>27</sup> regarding the status of WASH in their communities, their knowledge and awareness of vulnerable populations in their communities, and the access these individuals have to WASH services.

All six respondents stated that water and sanitation were key issues. All also reported that there are local committees on water and sanitation with which they work closely to ensure access to safe water. One headman also works with the Njola Mwanza clinic in collaboration with community health workers to ensure safe water for his community.

Several leaders were particularly active. One stated that he encourages his community to build toilets and to chlorinate water for drinking. He also uses his influence to encourage people to build dish racks and refuse pits, and raises WASH related issues in “all headman meetings with the Chief”. Another leader stated that he encouraged his community “to use protected water sources and use chlorine to treat the water”.

All leaders interviewed reported that many households in their communities had no toilets. Public toilets were also rare. In only one community the headman reported that public toilets existed in a church and in a school, and he believed that both of these toilets are accessible to vulnerable individuals.

Notably, several of these leaders have also been involved in efforts to improve the lives of vulnerable individuals in their communities. Four of the six community leaders interviewed also were aware that laws existed to protect people with disabilities, but there was less awareness about people with chronic illness such as HIV or AIDS. No community leader knew of any laws that specifically protected older people, although half of the respondents stated that these individuals were protected by the ‘same laws’ as everyone else.

None of the leaders, however, had linked their work with vulnerable individuals to their work on WASH issues. One headman was regularly in touch with a representative of a disabled person’s organisation (DPO), and another had in his community an active local disabled women’s cooperative for grinding grain; but discussions with the DPOs had never included WASH-related issues.

There was interest among all the community leaders interviewed in learning more. None had ever thought about the issue in depth, and had assumed that it was a matter of concern within or beyond the households of vulnerable individuals themselves. One headman said:

“Now that you raise this issue, it does make me think. We should do more. I know that these people struggle. To and from the well, (and) in the home too. And I see them going out to the bush sometimes. It is very hard. One old lady I know has to crawl to the bush when her daughter-in-law is not there to help her. It is not dignified; she should not have to do so.”

Another headman noted:

“I would like to know what to do about this situation. I really don’t know where to begin, but if someone could tell me, I would listen well.”

None identified access for vulnerable individuals as a key priority, but after discussion all were politically astute enough to realise this might be an area they should be concerned with.

### 3.12 Interviews with leaders or experts in ministries and sector groups

Four interviews were undertaken with government officials from ministries overseeing WASH. Additional meetings were held with representatives from the disability sector (four DPOs and two disability-specific NGOs), including a representative of the umbrella DPO, the Zambian Association of the Disabled (ZAFOD), representatives of organisations which represent or provide services to chronically ill individuals (AIDS, TB) and representatives of two organisations working on behalf of older adults.

The four senior representatives from the ministries overseeing WASH had not thought about vulnerable individuals in terms of accessible WASH beyond being aware that these were people who were difficult to reach. All four senior experts interviewed assumed that vulnerable individuals would benefit if WASH services were adequate for the community as a whole. As one senior expert stated:

“As part of general outreach efforts, particularly efforts targeting poor urban and rural communities, when these groups benefit, people who have trouble because they can’t move well or they don’t see well, will also be better able to collect water and to get to the toilet.”

The fact that newer ‘improved’ protected water sources (for example, boreholes with steps to the waterpoint, or heavier pump handles) might make it more difficult for some vulnerable individuals to access had not been considered by the WASH experts interviewed, and this information was met with concern on their part.

There was also interest expressed in getting more information on the needs of people with disabilities, those with chronic illnesses and older adults. The need for targeted efforts or for disaggregated data that would allow better monitoring and evaluation of how different groups of vulnerable individuals currently fare or will fare in future was not something that had been previously considered. However, ministry staff interviewed were quick to see this was an overlooked area that needed to be addressed. One official said: “I will need to know more so I can plan; my people will need to know more so they can plan as well.”

People from DPOs were especially responsive when interviewed on this topic. DPO representatives with physical disabilities and vision impairments quickly volunteered the fact that they ‘always worry’ about using the toilet. One leading disability advocate who is a wheelchair user noted:

“I go into rural areas to work with DPOs there regularly. But I always worry, all day long when I am there – will there be a bathroom I can use. Who can I ask to help me if I need help if the bathroom is too small or too far away? I don’t like to use the bush, but sometimes, it is all I can do.”

Another said:

“I never talk about this subject. It is considered too private. I would rather talk about national laws than toilets. But for many of us, it is a real issue that we need to be more vocal about. It will not go away.”

Advocacy groups that worked on behalf of vulnerable populations reported that there had been little or no contact with government ministries, NGOs or civic organisations that worked on water issues. One member of a disability advocacy community recalled that he had once tried to set up a meeting with some representatives from the WASH sector ‘around five years ago’ but ‘there was little interest and ‘no one had time to come to the meeting.’

An introductory meeting, (described in greater detail in the Discussion section) which brought representatives from the WASH, disability, chronically ill and adult groups together, and a follow-up meeting to present findings from this study to this group were well attended. Fostering such ongoing exchanges will be an important component of subsequent phases of this project.

## 4 Discussion

The findings of this study raise several important issues and concerns and provide understanding and insight into future avenues of action and advocacy for inclusive WASH efforts.

The implications of ensuring inclusive WASH for health and development, both of the vulnerable individuals themselves and the wellbeing and economic burden borne by members of their households who routinely help them, are widespread. It is striking that the overlap between the WASH sectors and sectors in health, development and human rights that advocate on behalf of vulnerable populations have previously largely overlooked this key area of development.

The primary focus of this baseline survey was to address research question 1: what are the problems and opportunities currently experienced by vulnerable people and their households in accessing and using WASH services?

This study has clearly shown that vulnerable individuals face inequity and inequality in meeting their WASH needs compared both with other members of their own households and households without vulnerable members in the same communities. Many of these needs could be met by addressing environmental, attitudinal and institutional barriers. Many of these changes could be made by adaptations that are potentially low-cost and low-tech. The result would be the potential for greater autonomy, and increased productivity and civic engagement among many vulnerable members of rural communities, and a corresponding reduction in use of time, energy and resources by other household members who provide support and assistance for many of these vulnerable individuals.

Large, extended households are the norm in the rural Monze District. This, in addition to relatively limited access to medical care and high rates of chronic diseases, increases the possibility of a substantial number of households having at least one vulnerable member with a disability, chronic illness or being an older adult. Vulnerable people tend to be less educated than the rest of the community. Although future research will allow more precise calculation of the actual rate of vulnerability in this population, it is clear that there is a current and growing need for WASH services that are fully inclusive and accessible.

This section discusses the findings presented in section 3. First, the barriers to WASH are analysed, putting forward potential solutions that might alleviate some of the issues presented. The impact of these barriers on the lives of vulnerable individuals and their families is then outlined.

## 4.1 Environmental barriers

### 4.1.1 Key findings

This research clearly shows that barriers to accessing safe WASH exist in the surrounding environment and society, and that they disadvantage vulnerable individuals and their families. Major environmental barriers identified are long distances and difficult terrain in reaching both waterpoints and toilets. Even if these were situated within reasonable distances, the designs of the waterpoints and the toilets make them difficult to use and might result in vulnerable people resorting to unprotected water sources, unsafe toilets and open defecation.

Although unsurprising, it is important to note that interest in making adaptations to WASH services was found to be almost wholly of interest to households that already had vulnerable members. Adaptations such as more accessible toilets or adequate water storage practices held little interest for heads of households without vulnerable members.

### 4.1.2 Potential solutions

Several simple solutions could be implemented to address the environmental barriers that vulnerable people experience when accessing WASH services:

- Improving accessibility of paths to waterpoints and handpumps; introduction of smaller water containers, or containers that can be rolled or pulled
- Storage of water within the household in containers that are easily accessible to individuals with physical limitations
- Adaptation of existing toilets: e.g., adequate paths, guide ropes, grab bars, raised toilets and adequate lighting to enable individuals to reach and use toilets on their own
- Improve access to water for bathing and the accessibility of washrooms to enable individuals to bathe more frequently

## 4.2 Attitudinal barriers

### 4.2.1 Key findings

The findings demonstrate that everyone, from vulnerable individuals to ministerial level experts, identify individual impairments and limitations as barriers to safe WASH services. These include physical limitations, weakness and ill health. Alongside this, most people, including vulnerable individuals, have rarely considered that they could do something about external barriers that prevent access to WASH. This implies learned helplessness borne from stigma, discrimination and exclusion.

People with disabilities are discouraged from touching water because of negative traditional beliefs that disability is contagious. Some disabled people thought that

their conditions were contagious. Consequently people with disabilities are teased and bullied, which resulted in isolation within the family or the community.

#### 4.2.2 Potential solutions

To challenge stigma and prejudices, efforts must be made to increase awareness and understanding of vulnerability, both within the household, and the community.

### 4.3 Institutional barriers

#### 4.3.1 Key findings

The research showed that vulnerable people face many institutional barriers. These include a lack of:

- Information about low-cost solutions to improve accessibility of latrines and water sources
- Inclusive standard designs for institutional facilities, e.g. communal waterpoints or school latrines
- Consultation with disabled and older people
- Understanding in the community about hygiene and sanitation
- Information in accessible formats (visual and oral)
- Knowledge and skills about accessibility and inclusion among relevant personnel, such as WASH implementers and health workers
- Awareness of disabled people's rights internally (WaterAid and implementing partner staff) and externally (community, NGOs, private sector, governments)
- Law, policies, strategies and guidelines on ways to ensure WASH implementation meets the needs of everyone in the community

#### 4.3.2 Potential solutions

Raising awareness and understanding of the barriers that vulnerable people face in relation to WASH among community leaders and government officials could increase their profile as key users of WASH services.

Information about how to make WASH services more accessible and inclusive could be disseminated to government officials, community leaders, and community organisations (such as local health clinics) and directly to households with vulnerable members. Community knowledge that adaptations can be made at any point is the first step in ensuring that WASH services are accessible and inclusive for everyone.

This study found strong interest at every level in improving the links between the WASH sector and sectors representing vulnerable populations. At the ministerial level and in NGOs, DPOs and advocacy groups that represent chronically ill and older adults, and among community leaders, there was strong interest in ensuring that WASH services are fully accessible and inclusive. It is important to emphasise that many of these

leaders had not previously considered these issues. The WASH sector and sectors representing vulnerable populations could interact more effectively. To that end, bringing together the WASH sector with advocates and service providers for vulnerable populations would be an important place to start.

Zambia has significant disability legislation in place. Policies and programmes should mainstream inclusive WASH to implement legislation. For example, in Zambia a government permit is required to dig boreholes. If a policy or regulation could be instituted requiring all new boreholes to be accessible (with clear guidelines about what accessibility for vulnerable individuals means), such a policy might quickly guarantee future access for thousands of households and vulnerable individuals countrywide.

However, the issue is not simply to make more policies or regulations, but to build a monitoring and evaluation system into those pre-existing frameworks.

Another method would be to introduce issues of inclusive and accessible WASH services in professional training. This could be achieved through collaboration between academics who work in social science, development and poverty issues including health and development issues, WaterAid, LCDIDC and local advocacy groups.

#### **4.4 The impact of the barriers on vulnerable individuals**

The barriers identified through this research and outlined above have day-to-day impacts on the lives of vulnerable people, going beyond the issue of accessing WASH services. These barriers affect their level of community integration, and their dependence on support networks, family members and caregivers.

##### **4.4.1 Reduced opportunities for community Integration**

Inaccessible facilities beyond the home, particularly toilets, are a real source of anxiety for disabled and older people when they are travelling or out in the community attending meetings, or socialising. This makes them more likely to restrict their movements and reduces their opportunities to participate in community life and contribute to society. Additionally, limited opportunities to bathe mean that disabled and older people are more likely to remain dirty and to smell, which exposes them to rejection or teasing, and leads to them being too embarrassed to socialise. Accessible WASH services in public spaces would increase the ability of vulnerable individuals to participate in the broader community, while also benefitting groups such as children, pregnant women and people temporarily impaired by illness or accident.

##### **4.4.2 Dependence of vulnerable individuals on support networks**

In all the areas examined in this study (getting water into the household, use of water for drinking and bathing within the household and access to the toilet), vulnerable individuals consistently called attention to their reliance on existing social networks. Many make strategic decisions, often on a daily basis, to forgo some of the assistance

that they need in order not to overtax their existing support networks, whether that is family members, neighbours or others.

#### 4.4.3 The roles of families and caregivers

The findings indicate that lack of access for vulnerable individuals to WASH services affects the family as a whole. The research showed that vulnerable people are more likely to be forced to continue open defecation, and to do so nearer to the house than others, thereby perpetuating the health risk posed by their faeces to the rest of the family and community. Additionally, exposure to dirt and faeces of people who crawl on hands and knees, coupled with lack of accessible hand-washing facilities, leads to poorer health, requiring medicine and care – a further burden on the family.

Insights from caregivers raise an important issue. A substantial number of tasks performed throughout the day for the vulnerable individual by the caregivers are related directly to WASH, including providing drinking water, assisting with toileting and changing soiled clothing or bathing. Providing assistance had specific implications for caregivers' own allocation of time, effort and ability to undertake other activities within their households, their communities and in the workplace. Additionally many caregivers are women or girls, which makes this a gender issue. Presumably, if access to WASH services were adequate for vulnerable individuals, not only would the individual benefit through increased choice and autonomy, but members of their immediate household would also benefit by having more time freed to undertake other household chores. Much of the labour within and beyond the household is largely non-monetary. The economic consequences of accessible WASH services that could free primary caregivers to undertake other activities that contribute to household wellbeing are difficult to estimate. However, according to caregivers, the cost of low-tech adaptations to make WASH services accessible for vulnerable individuals might be offset by the long-term benefits of caregivers having more time to devote to other income-generating activities.

In conclusion, it is evident that this is a development issue as well as a rights issue. With appropriate time, attention and collaborative efforts between sectors (WASH, advocates for vulnerable populations and service providers, public health and development officials), new and innovative programmes could make a difference to thousands of Zambian households. Such collaboration is long overdue, and holds immense promise for a brighter future for all.

## 5 Limitations of the study

This was a large and complicated study in which there was an attempt to collect a vast array of data relating to three separate but overlapping populations (disabled, chronically ill and older adults) in relation to access to WASH.

### 5.1 Data-collection tools

A range of new data-collection tools were developed, validated and used as part of this project. Some of these tools worked well, others collected data that was repetitive or could have been worded more clearly. The tools were revised and tested during the mid-term review and will be applied again in the evaluation.

### 5.2 Sampling

The original sample size, calculated on the basis of the local population size, was intended to be 350 households: 175 households with vulnerable individuals and 175 households without vulnerable members as a matched cohort. Time constraints, difficulties in locating 350 households and problems with data entry and cleaning led to the removal of some households where the results were unclear. The final total was 128 households with vulnerable members, and 116 households with no vulnerable members. The total of 244 households still represents a large sample size, but is not as large as had initially been planned.

### 5.3 Reliability of data

Every effort was made to ensure reliability of data through triangulation, e.g. by asking similar questions of different respondents, or by using different methods – structured observation and questioning – to improve confidence in the data collected.

However this cannot guarantee accuracy. For example, research<sup>28</sup> shows that people routinely over-report their level of handwashing,<sup>29</sup> especially in areas where effective public health campaigns have emphasised its importance. An interviewer effect is probably at play, whereby respondents have given answers they believe are ‘correct’.

Levels of open defecation might be higher than indicated by data from the questionnaires (Tools 1 & 2). When asked what type of toilet the household uses (Tool 1), respondents could only select one option, and are likely to have chosen a ‘more acceptable’ response. When asked whether they use the same toilet as the rest of the family, vulnerable individuals were offered a Yes/No option only. Adding ‘sometimes’ and ‘or defecation location’ would be more likely to capture these grey areas.

### 5.4 Problems assessing costs of accessibility

We were interested in assessing costs of making adaptations and building new latrines, in terms of time and material needed. This question proved more difficult than anticipated in an economic system in which time and labour is not always calculated monetarily. Furthermore, many of the necessary building materials can be collected locally, so questions relating to costs of construction or adaptation for latrines were not appropriate. Future research will need to explore these issues and the questions should be better adapted for the local context.

## 6 Future research

In addition to the limitations noted above, a series of questions would have added to the data collected and should be considered for future study, including:

- No questions were asked about MHM, although this is increasingly regarded as an important issue in the WASH sector. Future research should ask about this, especially because so little attention has been paid to menstrual hygiene management for girls and women with disabilities.
- Girls and women regularly cited fear of rape as an issue in using toilets, especially when practicing open defecation or needing to use the toilet after dark. Girls and women with disabilities especially are often at increased risk of rape, and more attention should be paid to their concerns and experiences with this in relation to their use of WASH services. Although rape is routinely addressed as a gender issue, a growing body of research shows that boys and men with disabilities are also at increased risk,<sup>30</sup> and their safety in relation to the use of WASH resources must also be considered.
- In Tools 1 and 2 we asked specifically about use of toilets by vulnerable individuals in terms of whether they used the same facilities as other members of the family, or used alternative places. In focus groups and interviews, vulnerable individuals indicated that they often used both family and alternative sources, depending on the time of day, how many people were at home and whether they were welcomed to use the family facility or discouraged from doing so. Similar alternating between protected and unprotected water sources was also noted. This is an area that would benefit from future investigation.
- As noted in the limitations section, it was difficult in this study to assess costs of adaptations, especially low-cost adaptations that could be done in the household. This is a crucial area of future research: if we are better able to put a 'price tag' on such adaptations (this grab bar can be installed for only a small cost and in little time) household heads might be more willing to consider an adaptation. Vulnerable individuals interested in getting family members to install an adaptation would benefit from having the information they need to make a strong case for why the household should spend money on adaptations.

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- 11 These tools were refined for data collection during the mid-term review.
- 12 Teachers were selected based on their availability at the time of the interview, with the idea that information gathered would represent the understanding of teachers. This sample included: one senior teacher, one deputy head teacher, one guidance teacher and two classroom teachers.
- 13 Growth centres have at least 2,000 residents.
- 14 For readability, figures have been rounded off to the nearest whole number; however, the exact figures are depicted in charts and graphs.
- 15 Respondents could give more than one answer leading to a total of more than 100.
- 16 The low rate of glasses and hearing aid use reflects the lack of availability of such devices and not necessarily the need for such devices, which might be higher.
- 17 This finding is interesting because it has been suggested that, in times when water is scarcer and the time and energy needed to travel to collect water greater, vulnerable individuals might be more likely to use unsafe sources of water, closer to home (Groce et al 2011).
- 18 Clorin is a household water treatment product sold by Society for Family Health (PSI's affiliate in Zambia).
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