This research aims to understand the barriers and opportunities that disabled and older persons with additional access requirements may face using standard WASH facilities. An action research approach is being used, which applies a mixed methods approach to gather evidence before and after WASH interventions in one Ward in Zambia and in two Districts in Uganda, to assess the impact and benefits for the target group. This paper provides an overview of the preliminary baseline data findings, how these have been used to inform the planning and re-design of the WASH programmes to respond to identified barriers and needs, the analytical framework and participatory process used to analyse preliminary findings, as well as some of the key inclusive WASH activities that now form practical action plans in both country programmes.

Introduction and background

Progress on the MDGs is not equitable with the poorest often experiencing minimal benefits from improvements in water and sanitation (UNICEF, WHO, 2012). National surveys disaggregate data related to urban / rural location, wealth, gender, religion / caste / ethnicity / language and education of the household head, but rarely for disability (Trevett and Luyendijk, 2012). Therefore the extent to which persons with disabilities lack access to safe water and sanitation is often unknown. A growing body of evidence indicates that persons with disabilities and their families are more likely to experience economic and social disadvantage (such as higher rates of unemployment, increased medical costs, and lower school attendance for children), compared to those without a disability (WHO, 2011). Similarly, water insecurity is a major source of stress and often expense for poor older people. A lack of access to safe water and basic sanitary services can exacerbate impairments and poverty for persons with disability and for people living with chronic illness (Fisher & Jones 2005, Groce et al 2011). Small-sample studies have looked at the effects of pilot projects specifically targeting persons with disability in WASH programmes (Wilbur, 2010, Wapling, 2012), but there is no evidence about the benefits of inclusive approaches at scale. This research aims to contribute to filling this knowledge gap.

Aims and research questions

The aim of the research is to understand the barriers that persons with disabilities, chronically ill and frail older people (collectively referred to as ‘vulnerable’ people in this paper) face when attempting to use standard WASH facilities in low and middle income countries, by answering the following 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 first research question is answered under the ‘preliminary findings’ section; responses to the other research questions are not included in this paper.

**Research design**

A pre-intervention baseline study gathering quantitative and qualitative data in both countries precedes WASH interventions in Mwanza West ward in Zambia’s Monze District and thirteen sub-counties in Amuria and Katakwi Districts in Uganda, where WaterAid partners are already implementing WASH programmes. A post-intervention study will be completed to assess the impact and benefits of the intervention for the target group. The action research approach is being implemented. The process of implementing an inclusive WASH programme is also being monitored throughout the project.

**Who is involved**

This project is a collaboration between WaterAid, WEDC and Leonard Cheshire Disability (LCD). The Appropriate Technology Centre (ATC) in Uganda, and Institute of Economic and Social Research (INESOR) in Zambia are the research partners. In Zambia the national NGO, Development Aid from People to People (DAPP) and the local government are implementing the inclusive WASH intervention. In the Amuria and Katakwi districts in Uganda, WaterAid will work with the District Local Governments and partner NGOs Wera Development Association (WEDA) and The Church of Uganda Teso Diocese's Planning and Development Office (CoU-TEDDO) to implement the WASH intervention.

**Baseline data design**

The collection of the baseline data research began in January 2012 in the target populations in Zambia and Uganda, prior to WaterAid’s intervention. LCD led the baseline study and developed nine data collection tools in collaboration with WaterAid and WEDC. LCD provided disability awareness training to the research partners, and supported partners to carry out the baseline data collection. Research participants were selected through a systematic sampling approach. 175 households with a vulnerable member and an equal number of control households (i.e. households in the same geographical areas not including any vulnerable member) were identified from village-level lists of households maintained by local government. Data collection methods included a quantitative household survey, in depth semi-structured individual interviews, focus group discussions (FGDs), key informant interviews, and latrine and water-point observation school and household checklists. Currently quantitative data collected in both countries are undergoing a data cleaning and cross checking procedure.

**Preliminary findings**

This section answers the first research question: what are the problems and opportunities currently experienced by vulnerable people and their households in accessing and using WASH facilities? (The barriers are explained in Table 1).

**Environmental barriers**

Preliminary analysis highlighted some issues related to water and sanitation accessibility. The main difficulties when collecting water relate to distance to travel to water source, difficulties using heavy pump handles, and challenges to carrying heavy water containers over long distances. In both countries, some vulnerable respondents reported that they do not use the same toilet as other household members. Reasons given include the length of time it takes to get to the toilet, the lack of privacy the facility provides, the physical inaccessibility and the lack of support structures. One informant in Uganda said “if the entrances of the latrines were made flat, the rooms made wider and the latrines made with a provision of where to sit and also have handles that it would be to an advantage”. A number of informants commented that public toilets are not accessible (e.g. steps to the toilet, no handrails or toilet seat inside and a lack of space to turn around) and when selling goods in markets, they may be forced to relieve themselves in the bush. One Ugandan informant explained: “I am a councillor for the disabled but I was [once] in a meeting but I couldn’t go to the latrine yet I had gotten an urgent call, I tried enduring but ended up urinating on myself, I felt so humiliated that I have never gone back for a single meeting.”

**Attitudinal barriers**

Certain respondents highlighted the stigma they sometimes face when attempting to access water points, either being discouraged from using the water source, due to being considered unclean; being forced to wait longer in line, or to simply go without. One Ugandan informant explained, “The lame people are not allowed to use wells because they are considered to be dirty. We have to wait till everyone has finished
fetching, or maybe somebody sympathetic can offer to help, but that is once in a while.” Given these issues, vulnerable people reported having to resort to using unclean sources. This may lead to further disabling illnesses or disease. During FGDs in Uganda, informants spoke about the discrimination they face when attempting to use toilets: “people don’t really let us share the latrines with them because they think we are dirty and think we usually dirty their latrines, so the bush is the only place we opt to go to”. Being viewed as ‘dirty’ by the wider community, may negatively affect people’s dignity and therefore ability or desire to take part in community activities. This can lead to lower self esteem and limited willingness to assert their rights, including their rights to access appropriate WASH services.

Organisational / institutional barriers
In both countries, some vulnerable people indicate that they do not collect water for the household, since they are considered too weak, disabled or sick to do so. This may suggest that the community is generally not aware of how to make facilities more accessible for vulnerable members. A major barrier to access is a lack of information, including accessible information formats, about low cost ways to make facilities more accessible. There is also limited information on accessible designs, meaning that people do not know what is possible (see column 2 of Table 1).

The process of developing an inclusive WASH programme
The capacity of practitioners to design an inclusive WASH intervention to address barriers faced by vulnerable people was developed over several stages. Methods included providing technical training, carrying out participatory barrier analysis and stakeholder analysis, follow up training and support for monitoring.

Technical training
In 2010 and 2011 WaterAid and WEDC collaborated to provide awareness raising and technical training to WaterAid staff and partners on delivering inclusive WASH. Most, but not all of the WaterAid staff and implementing partners involved in the study took part in this training. (Materials developed in the course of this training are now available open source (Jones 2012).

Using preliminary findings to inform planning of WASH intervention
During July and August 2012, WEDC visited Zambia and Uganda to hold a week-long series of meetings and community visits with WaterAid staff, partners and external stakeholders. The purpose was to present the preliminary baseline findings, to analyse and identify ways to address the issues identified through the WASH intervention together. Community visits enabled WaterAid, WEDC and implementing partners to discuss the intervention with community members, understand the barriers household members face in relation to WASH, and review any facilities developed (Figure 2). This added stark reality to ensuing discussions. A key analytical tool used was a participatory barrier analysis. Implementing partners, WaterAid, WEDC and district stakeholders (including DPOs, INGOs, district and national governments) gathered to discuss the research project, the implementation, and conduct a participatory barrier analysis. The latter involved an initial presentation of the preliminary baseline findings, followed by a facilitated group discussion of the issues. Participants categorised issues according to whether they were environmental, attitudinal, or organisational / institutional (column 1&2 of Table 1). Next, they suggested solutions to these barriers, and developed an action plan to realise the solutions (column 3).

<table>
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<th>Table 1. Highlights from the barrier analyses</th>
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<td><strong>Barrier</strong></td>
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Organisational / institutional Lack of law, policies, strategies and guidelines on implementing inclusive WASH; lack of information on inclusive technology; lack of accessible information (visual, oral) and consultation with vulnerable people; limited awareness of disabled people’s rights internally (WaterAid and implementing partner staff) and externally (community, NGOs, private sector, governments) Advocate for inclusive WASH at a national level and influence other sectors (e.g. health) to integrate WASH into their programmes; develop accessible designs and guidelines, and train local masons on the construction. Provide demonstration accessible latrines; IEC materials to include information on vulnerable people in accessible formats (posters, pictures, radio) to raise awareness; ensure effective participation of vulnerable people in the total project cycle; raise awareness on rights for persons with disability and older people and collaborate with different organisations representing vulnerable groups.

In Uganda the team also conducted a stakeholder analysis in which participants identified individuals involved at the community level; this helped the team develop their plans. Each stakeholder was placed on a chart within the proximity of the household, depending on how directly or closely they should be involved in the project. Figure 1 shows the community level at the bottom, with the household in the centre, and the relevant community level stakeholders on either side.

**Constraints encountered**

Staff in Zambia were enthusiastic and committed, and at the time of the planning visit had already started implementing solutions. Due to staff turnover however, some staff had not completed the equity and inclusion training, leading to a lack of guidance and clear direction. Raised toilet seats had been designed and constructed for several older people and persons with a physical disability. These were very effective, and the recipients were delighted, but these individual solutions required high inputs of staff time and resources, so are unsustainable in the long-term. It was also apparent that the ‘disability’ project was viewed by staff as separate from their main WASH programme.

**Follow-up training and support for monitoring**

To address these points, a follow up workshop was held in November 2012 with partners and community members to provide a more holistic understanding of inclusion. This placed greater emphasis on attitudinal and institutional barriers (see Table 1), and how these could be addressed through ‘software’ components of a WASH programme. Based on the solutions from Table 1, a checklist of what could constitute inclusive WASH activities was developed and used for participants to ‘audit’ their own WASH action plans (Box 1).

A series of meetings were also held in both countries to develop five process monitoring tools. These tools capture the time it takes for implementers to carry out activities in an inclusive way compared to a non inclusive way (ie the additional time taken to consult with people who have difficulties communicating compared to non disabled people), monitor levels of participation of vulnerable people in community meetings and their ability to influence decision making. The tools also allow practitioners to assess their own capacity and capture successes and challenges faced.

In order to effectively influence key policy and decision makers to mainstream inclusive WASH the teams conducted outcome mapping in Uganda, Zambia and the UK. Rather than focusing on direct deliverables,
outcome mapping focuses on the behavioural change of key individuals, groups or organisations that the teams are seeking to influence through this project (Jones and Hearn, 2009).

Box 1: What does inclusive WASH look like?

Inclusive WASH promotes an approach that responds to the varying needs and requirements of people and the local context, rather than promoting a ‘one size fits all’ approach. An inclusive approach means that:

1. **Community mobilisation** uses participatory approaches that enable different groups to take part, including those with less power.
2. **Information about sanitation and hygiene** includes facts about menstrual hygiene, disability and impairments and communicable diseases. It challenges stigma and discrimination and reinforces the need to provide access to all.
3. **Information is provided in local languages and accessible formats with** pictures for people who cannot read, and audio for people who cannot see. Everyone has access to relevant information about WASH technology options.
4. **WASH facilities that provide privacy** for women to wash their bodies, stained clothing and any cloths used for menstrual hygiene management.
5. **Public water sources** are located and installed in a way that makes them as accessible and user friendly as possible for everyone.
6. **Public or institutional latrines** in markets, schools, health centres have separate and accessible facilities for males and females. Water is provided inside the women’s cubicles for menstrual hygiene management.
7. **There are arrangements for the disposal of sanitary napkins.**
8. **Water user committees** include women and members of other marginalized groups, such as persons with disability. Meetings are facilitated to ensure meaningful participation.
9. **Tariffs include options** for the poorest and people who cannot pay.

Changes agreed to make WASH intervention more inclusive

Drawing on the results of the participatory barrier analysis (see Table 1), WaterAid and its partners developed an inclusive WASH programme for implementation in both countries. The intervention aims to address environmental barriers by constructing boreholes with access ramps leading to the well apron, and widening entrances and circulation space around the handpump. Institutional latrines will be accessible and provide privacy for women to wash their bodies, stained clothing and any cloths used for menstrual hygiene management. Information about latrine design options will include seats (static and / or movable), handrails and access ramps. Planned Community Led Total Sanitation (CLTS) will follow the same steps as in any other CLTS project (i.e. triggering, developing community action plans and training hygiene promoters), but mobilisers will structure discussions around the barrier analysis to raise awareness for the differing access requirements. This will work towards breaking down attitudinal barriers. Information will be developed with pictures for people who cannot read; audio for people who cannot see and it will be in an appropriate language so that everyone has access to relevant information. This will help challenge institutional barriers related to a lack of accessible information.

Lessons and conclusions

The process of barrier analysis was highly participatory, which served to raise awareness of the issues facing vulnerable people and effectively engaged the stakeholders, so that they are more likely to collaborate in the future. Developing action plans together and assigning tasks to stakeholders increased engagement and highlighted when and how different stakeholders should be involved.

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References

Note/s
Materials developed in the course of this training are now available open source (Jones 2012). An example of one tool developed through the capacity development process is the inclusive WASH checklist for practitioners to apply when designing, monitoring and evaluating their work. In effect, it can be used as a self auditing tool.

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