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MEDICINE



Photographing the unspoken

A photo exhibition depicting the daily struggle faced by people with disabilities in accessing water, sanitation and hygiene.

Today when you went to the toilet it probably wasn't something you thought about a great deal. When you had a shower it was probably a pleasant experience. When you needed to wash your hands or change your sanitary pad you probably didn't feel embarrassed.

But what if you were Reza, a 24 year old single mother and double amputee who shares her make-shift toilet with 18 others? What if you had to crawl into that toilet, putting your hands in the urine and faeces of others?

Reza doesn't talk about it.

What would you do if you were Blessings, an elderly woman with albinism? What if you had to leave your house at dusk each morning to collect water just so that you could avoid painful skin damage? But what if travelling to the water point at that hour put you at risk of rape because locally people believe that having sex with an albino will cure HIV?

Blessings takes the risk – she has been raped.

How would you manage if you were Lizzie, the mother of Samson, a teenage boy who has profound cognitive and physical impairments and who is incontinent? What if your full time role was to care for him, to lift him to the bathroom and wash him 5 times a day? What if your caregiving role meant that your family members could never hold down a regular job? What if it meant that your free time was taken up collecting extra water (more than double other families) and your meagre income was largely spent on water bills?

Lizzie compromises on her own water use and needs.



“You can see the blue bucket, that’s what normal people carry”

Eves, who has partial paralysis due to having polio as a child.

About this exhibition

The photos showcased in this exhibition were taken by **Pricilla Chisale, Evess Ngwira, Hovings Chiumia, Wezzie Mhango** and **Hermes Tebulo** all of whom have a disability. Each participant was given a camera and trained in basic photography skills. They were asked to take five pictures of the most challenging aspects of their daily lives - the things they would most like to be able to do without relying on others or feeling different. Although they were not told this was a study on WASH, these issues emerged as dominant challenges in their lives. The research which took place in 2014 included 36 people with disability and 15 carers for people with disability. It was designed to explore the extent to which WASH access is regarded as a problem by people with disability, how they experience the impact of WASH access on their lives and what mitigation strategies they use.



“Even though I am able to fetch some firewood I am unable to get enough water for my needs as I can only carry a small bucket.”

Wezzie, who is a single leg amputee

“Most people never think about pathways. But its my right to have access to better roads to be able to fulfil my goals and be independent.”

Pricilla, who is blind



15% of the world's population have a disability

Among the poorest populations in low income countries as many as 1 in 5 individuals are likely to be disabled.



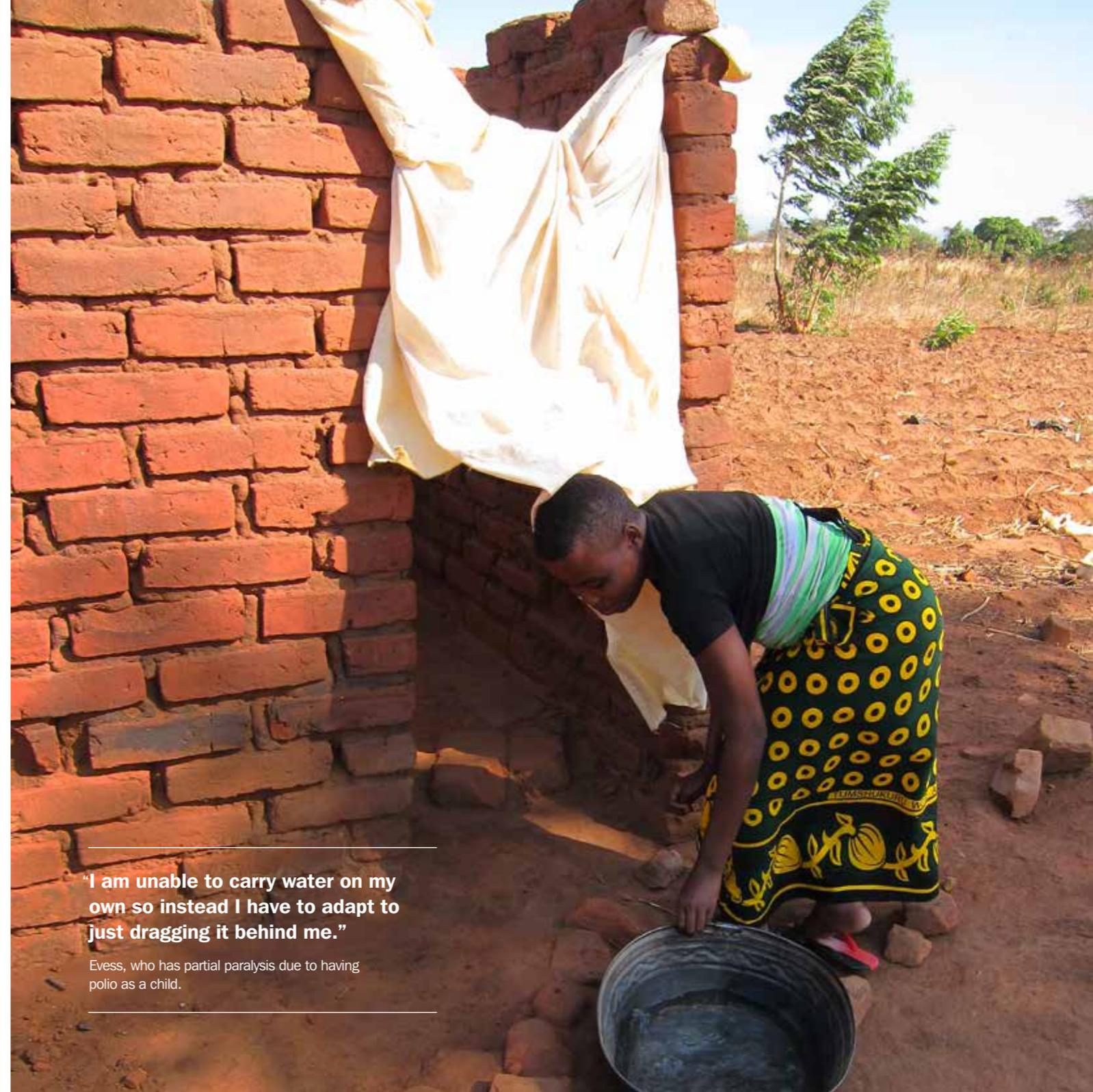
Their households are more than 5 times more likely to lack improved water access and more than 3 times more likely to lack adequate sanitation compared with households in the highest wealth quintile in the same country.

The new Sustainable Development Goals aim to provide access to water and sanitation FOR ALL. Achieving this will require reaching the hardest to reach, the most poor, and those whose water, sanitation and hygiene (WASH) needs are currently not addressed by mainstream programming. A large portion of these unreached individuals are likely to be people with disabilities.



“This depicts the bathroom when it is wet. It makes me unhappy when it is like this because I have to crawl, but our bathroom is shared with other families so its normally like this. If I had the change I would like a bathroom of my own so I could keep it clean.”

Hovings, who became a double amputee following a road accident.



“I am unable to carry water on my own so instead I have to adapt to just dragging it behind me.”

Evens, who has partial paralysis due to having polio as a child.



“You can see how unhappy I am in the toilet. I have to crawl and it is really unhygienic. I know I am putting myself at risk of infection but what other option do I have?”

Hovings, who became a double amputee following a road accident.

What we learned:

- All of the people with disabilities that participated in this research reported at least one WASH access challenge.
- Most said WASH-related activities were among their top 3 biggest challenges of daily life and several said that all of their top 3 challenges were WASH-related.
- Carers also reported that WASH-related activities form the dominant and most taxing part of their caregiving role.
- None of our participants reported ever having been asked about WASH access before, even those who were receiving support from government organisations and civil society organisations.
- WASH access barriers were found to vary significantly by impairment, gender and geographical location.
- Improving WASH access is not just about changing physical infrastructure. Many people with disabilities are excluded because WASH programs are not delivered in a way that enables their attendance, understanding and participation. For others their ability to access WASH equitably is affected by social beliefs and the ways institutions and community structures operate. For some individuals medical support and home-based care is essential for improving their situation.
- Considering the needs of people with disability does not add significant cost to program delivery and there are a range of cheap adaptations that can be made from locally available products.



“People need to think about us when they are planning. Drains and pipes are barriers that we cannot pass over. It’s sad because it stops me going to the market and other places I would like to be.”

Hovings, who became a double amputee following a road accident.

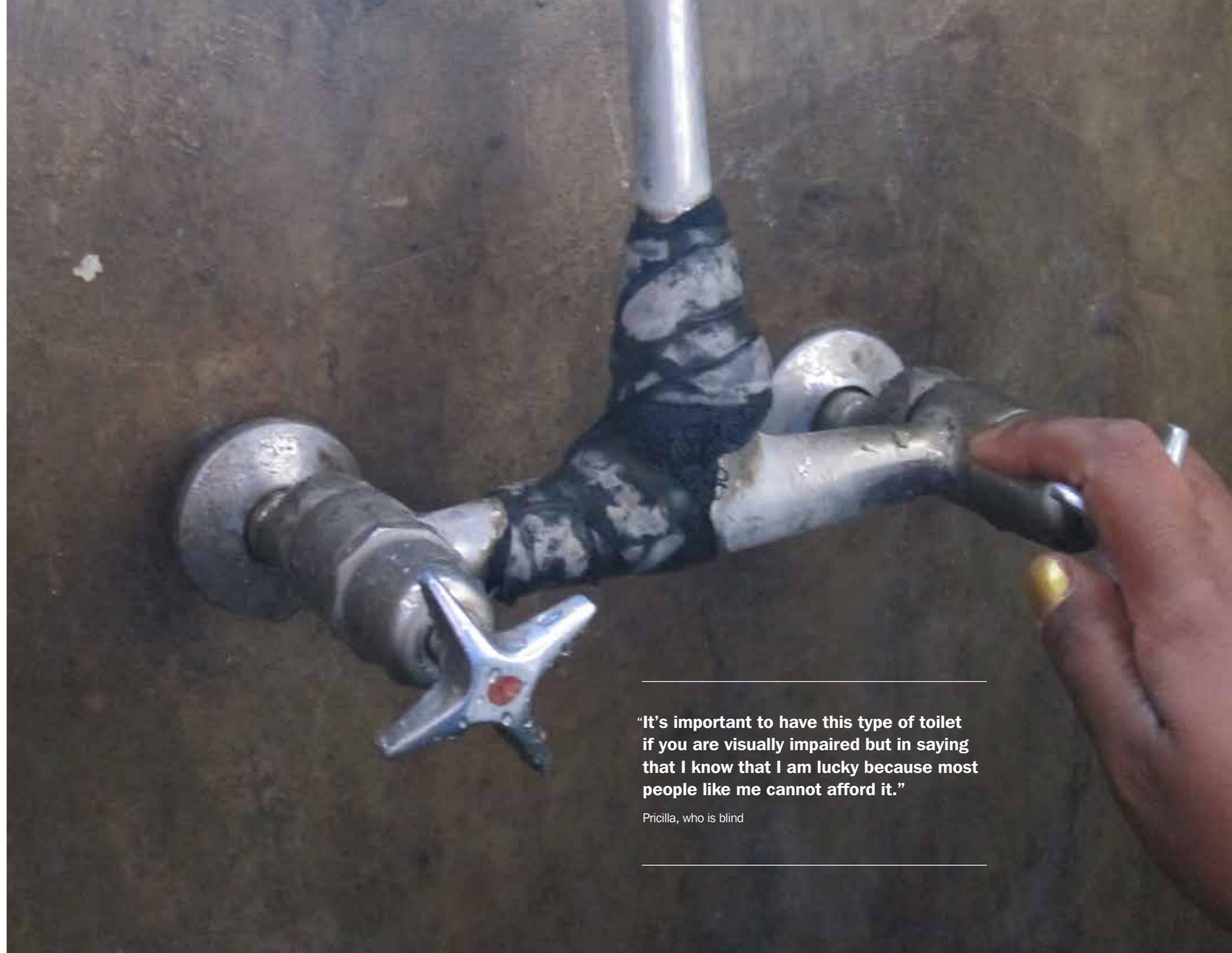


“A tough moment after having a seizure is my clothes are dirty and stinky so I need to wash them more than other people do.”

Hermes, who has epilepsy.

How can we change the situation?

- Take time to ask people with disabilities about their WASH access needs.
- When planning programs or building infrastructure consult people with disabilities at every step of the process.
- Actively adjust the way programs are delivered to ensure inclusivity.
- Encourage the development of local support networks for people with disability so that knowledge can be shared.
- Share information about cheap adaptations that can be made from locally available materials.
- Monitor the effect WASH programs are having on vulnerable groups such as people with disabilities.



“It’s important to have this type of toilet if you are visually impaired but in saying that I know that I am lucky because most people like me cannot afford it.”

Pricilla, who is blind

For more information visit:

ehg.lshtm.ac.uk/wash-disability/
wedc-knowledge.lboro.ac.uk/collections/equity-inclusion/

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