HOW EXCLUSION IN SANITATION PROGRAMMING



The sad story

"When I have diarrhoea, it is best that I spend the days and nights nearer to the latrine so I can be able to quickly roll to ease myself. Short of that, I would never make it to the latrine in time.'

Such is the story of Naome Sababu, a 30-year-old woman who has lived almost all her life with impairment in both her arms and legs. Her only mode of motion is by dragging herself by the buttocks. She suffered a measles attack when she was nine months old and has been paralysed.

When I arrived at her home, which is approximately one mile up the Rwenzori Mountains, I found her seated by the veranda of her mud-and-wattle house; helplessly looking at her sevenyear-old nephew, Benjamin

Kato. Kato, too is paraplegic and was soundly resting in a pool of goat excreta. This sight of the helpless boy in such a dirty environment shocked me so much that I had to excuse myself from my guide for a while as I gathered the courage to return and probe how these two impaired residents of Kibagha-B. Nyakitokoli, Karangura subcounty, Burahya county, in Kabarole district are managing to get by in such deprivation.

Karangura is located about 16km from Fort Portal town, 10km off Bundibugyo Road. The villages in Karangura sub-county are far-flung areas bordering and in the middle of the Rwenzori Mountains, where families commute long distances of 2-3km in search of clean water

recent annual assessment and community visit done by Water Charity, a nongovernment organisation, discovered that out of the eight schools in and around the Rwenzori Mountains, none has a nearby water source.

The children in these schools drink dirty water from faraway rivers. This poses a risk of contracting waterborne diseases such as diarrhoea, typhoid and cholera by school-going children.

But for children like Benjamin Kato of Karangura sub-county in Kabarole district, who cannot go to school because he is paraplegic, the situation is even worse. The sevenyear-old lives in abhorring sanitation conditions and is unable to access water by himself.

After Kato's uncle (and my guide), Elikana Kahuzo, quickly picked him up, I noticed a freshly wetted patch where Kato was laying; prompting me to ask whether it was his urine.

Yes, that is his urine. Kato eases himself wherever he gets the urge because he cannot move himself to the latrine. He cannot speak, so it is even difficult for him to call out for help whenever he wants to go to the latrine," Kahuzo says.
Nathan Kahuzo, Kato's father, says

the seven-year-old cannot walk or sit on his own due to a neurological

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impairment. The family was told that he got the problem as a result of a delayed delivery process, which his twin sister was lucky to survive. She is now studying in P.1 at a school down the mountain.

Naome Sababu, 30, also a resident of Karangua sub-county, relies on young children like Kato's sister to fetch for her water. "If the children are not around, I have to wait until they are back. Going to the latrine, I have to drag myself by the buttocks at a," she says in a tone that hardly hides her pain. The latrine she uses in used by about seven other members of the family, including children who defecate and urinate around the pit.

But, Kato and Sababu's anguish is just, but a small representation of what several more persons living with disabilities (PWDs) around the country go through to access water and sanitation services. Many argue that they have been left out and only cling by a thread of hope that the situation could change for the better someday.

According to the 2014 Uganda Population and Housing Census report, 4,096,477 (12.5%) of persons had at least one form of disability. This is too considerable a number of people to be ignored and left out in national social service programming.

Lawrence Kagenda, 14, a resident of a neighbouring village in Karangura, says the Government has neglected people like him in various programmes, including sanitation. When I met him, he was being pushed by his friends from school on his wheelchair, perhaps going home to have lunch. "I find it a

challenge accessing water or the latrine in instances where there is no one to help me, he laments. Asked how he goes PWDs in urban centres can be given facilities where they can access services

And for Evelyn Nyakaisiki, who has a hearing impairment, the inability to have enough money to pay for safe

Kagenda says he moves on his knees, which in most cases leaves them swollen and very painful.

The distance from his home and the nearest water source is about 200m and he says accessing the source on his wheelchair is troublesome. He survives on the mercy of fellow children who fetch water for him.

At school (Kazingo SDA Primary School), he uses teachers' latrines because they appear cleaner since they have a concrete slab.

> water at a nearby tap stand has remained her biggest challenge to accessing safe clean water. A tap stand was constructed in her village, but she still has failed to access the clean water because she is required to pay a monthly maintenance fee

> > afford. are told that if we

of sh2,000, which

she cannot

cannot pay that money, then we should not use the tap water," she says. Nyakaisiki has since stopped using the tap water and risks her life by fetching muddy water from the nearby river Mpanga. Most people in this village have also resorted to using the unsafe river water.

SIMILAR SITUATIONS

Taking a look at the situation in urban centres, one would expect that life is a little better for the PWDs, but living in such areas also comes with its challenges.

For Happy Simburiregye, a person with disability and resident of Fort Portal town, parting with money to access a sanitation facility is

something he has vowed never to do. He has been on the Fort Portal streets for about three years now, having moved from Bundibugyo. Simburiregve says he faces a challenge accessing toilet services within the town because most of the facilities are built with steps (stairs) made of usually slippery tiles, yet he cannot climb them without help. To make matters worse, he has to part with some money to access the toilets yet he hardly earns a shilling.

"The truth is, I do not have money. But even when I have little, I would rather spend it on getting what to eat than pay for toilet access. I, therefore, find places where there