

Leave no one out

Reaching people with disabilities and leprosy with water, sanitation and hygiene: WaterAid Ethiopia's experience

Introduction

This paper shares WaterAid Ethiopia's experience of mainstreaming the water, sanitation and hygiene (WASH) needs of marginalised and excluded people, including those with disabilities, in its work and that of its partners. It will establish the links between WASH and disability and leprosy by presenting cases from a WaterAid Ethiopia supported project. To strengthen its work on equity and inclusion



and ensure the WASH rights of all, including people with disabilities, WaterAid started to mainstream the WASH needs of marginalised and excluded people in its programme and policy work in 2010. One such initiative is partnering with specialised organisations working on disability.

WaterAid is currently implementing a three-year inclusive urban WASH project with Cheshire Foundation Action for Inclusion. The project aims to address the main WASH challenges faced by most disadvantaged and marginalised urban slum dwellers, including people with disabilities, children, older people and women, by constructing inclusive WASH facilities, promoting hygiene, and offering training and technical support. The project includes both community and school projects, and has so far benefited around 15,000 people, of which more than 15% are people with disabilities, including those affected by leprosy. The project is implemented in a slum area of Addis Ababa, Ethiopia's capital city, home to one of the country's

largest leprosy colonies. The colony is home to leprosy-affected people who have migrated from different parts of the country looking for medical services from All Africa Leprosy, Tuberculosis and Rehabilitation Training (ALERT), the main hospital in Ethiopia providing specialist medical care for leprosy complications.

Disability in Ethiopia

Disability is a major public health problem in Ethiopia. Official figures state that 1% of the population is disabled (according to the 2007 population and housing census in Ethiopia) but this is widely considered to be an under-estimate. This under-reporting of disability is likely due to negative attitudes, and different interpretations and misconceptions of the word 'disability'¹. According to the 2011 World Health Organization estimate, around 15% of the world's population lives with some form of disability. The same report estimates the prevalence of disability in Ethiopia to be 17.6%, or approximately 14 million people. Generally, the main causes of disabilities in Ethiopia are war and landmine injuries, accidents and diseases. The most common type of disability is visual impairment, followed by other physical disabilities. In Ethiopia, as in other poor countries, disability causes poverty and is also a result of poverty, because of its connections with disease, inadequate healthcare, conflict and discrimination.

Leprosy in Ethiopia

In Ethiopia, it is estimated that over 30,000 people are living with a permanent leprosy-related disability. Almost 5,000 new cases are diagnosed every year. Leprosy often affects the poorest of the poor, and if not diagnosed early, leads to disability, which affects people's ability to support themselves financially. In Ethiopia, people affected by leprosy live in basic shelters with inadequate water and sanitation, because of poverty, exclusion or the inability to assert their rights to these basic services. Leprosy is sometimes not fully understood by communities due to myths, superstitions, ignorance, misunderstanding and stigma surrounding the disease.

ALERT is the main hospital in Ethiopia providing specialist medical care for leprosy complications, including reconstructive surgery, eye surgery and the treatment of complex leprosy reactions. It also offers training courses to help medical personnel increase their leprosy expertise². Leprosy was integrated with the general healthcare system in 1995. At highest risk

¹ Ministry of Labour and Social Affairs (2010)

² See www.leprosymission.org/ethiopia.html

are those living in endemic areas with poor conditions, such as inadequate bedding, contaminated water and insufficient diet, or other diseases that compromise immune function.

The links between leprosy and WASH

As literature shows, people at highest risk of leprosy are those living in endemic areas with poor conditions, such as inadequate WASH, insufficient diet and poor housing conditions. This all contributes to weakening the body and compromising the immune system, increasing vulnerability to disease. Although the way in which leprosy is transmitted is not well-understood, it may be argued that if the body's natural defences are already weakened by disease (including WASH-related infections) then it is easier for the leprosy bacteria to take hold. Treatment and prevention depend on personal and environmental hygiene conditions and the stability of the immune system. Cleanliness and general hygiene also prevent the spread of leprosy³.

Why WASH is crucial for people affected by leprosy – experience from the project

Dialogue between WaterAid Ethiopia and the users of the three-year inclusive urban WASH project revealed that WASH is crucial in improving health and wellbeing, reducing inequalities in the general population and, specifically, discrimination towards those affected by leprosy.

Water

Clean water is important in multi-drug therapy

Although there is no vaccine, leprosy is curable with multi-drug therapy (MDT). Within two weeks of starting MDT there is no risk of the disease spreading to anyone else. However, these drugs need to be taken with safe water for either six or 12 months to be fully effective.

Case study 1

“I am Alemayehu Abat. I am 50 years old. I have lived in this locality for about 20 years. Before the start of the project we used to collect water from an unsafe source. Safe water is very important for people affected by leprosy. We are always told by the clinic to take the medicine with safe water; this was not possible in the past years as we collected water from the Akaki river.”

³ Kerr-Pontes L R S and Barreto M L (2006) *American Journal of Dermatology and Venereology*

Close and accessible water points save energy and money, and improve health

In the past, women in the area, especially those with disabilities, found it difficult to collect water, having to walk 20-30 minutes to the Akaki river every day. The walk was perilous, and women often fell while carrying heavy jerry cans, resulting in injuries. Those unable to carry the water themselves would have to pay others to assist in water collection – money taken from very small incomes from begging.

Case study 2



“My name is Beletu Demmise. I am 70 years old. I came here from Sheno looking for medical care. I am divorced due to complications related to my sickness. Even though I was disabled from leprosy, as a woman I had to do the household chores, and water collection was one of my responsibilities. Going to the river was very hard as a disabled person, and it used to worsen my wounds. Over time, not being able to accomplish this task frustrated me.

Additionally, many people, including me, used to suffer diarrhoea from drinking unsafe water, which affected our health and had an impact on our livelihoods. Now, thanks to the project, we are healthy and our children are healthy.”

Case study 3

“My name is Alem Bishaw. I am 50 years old. I came here long ago seeking proper medical care. I faced stigma and discrimination where I was born. When I became disabled, I couldn’t collect water, but now, with this project, I can. This stops me being dependent on others. In the past, even though I had four children, they were all small and could not support me with water collection, so what I had to do was pay for people to collect the water in jerry cans. I used to pay



three birr per jerry can and this was from the meagre income I earned from begging. It has been two years since I started to benefit from this project. It is accessible to me and other people with disabilities. Now, with the project near to my house, I can easily go and collect water in a ten litre jerry can whenever I want. Regarding toilets, I find the new toilet very comfortable as it has a raised seat so that I don’t have to bend my legs, which is very difficult to do. It also has a rail to support me to get up for

dressing. In the past, I sometimes went to the ALERT hospital just to use the toilet. Now that time has passed and a better day has come.”

Water is critical for hygiene for treating leprosy

People affected by leprosy also mentioned the need for good hygiene in treating and caring for the affected parts of the body, saying that many problems can be prevented if good hygiene is observed at home and in the workplace.

Case study 4



“My name is Italem Haile. I came from a place called Gojam seeking medical treatment at ALERT hospital. Just like many of us, due to the frequent visits I was making, I finally decided to settle here. At the hospital I am told to soak my legs and hands in clean water for about an hour daily, and then to oil them. Otherwise the wound will crack and become easily infected. We also need clean water and soap

for dressing the affected area. This was not possible in the past when we collected dirty water from the river. We didn’t have enough clean water to treat and care for our affected legs and hands. Now, I can easily access clean water, a toilet and a shower. This all improves my situation very much. My artificial leg needs to be cleaned regularly so that it does not smell. This bad smell forced us not to mix with people in the past. Now we are healthy and clean and feel equal to other people.”

Sanitation

Before the start of the project, people used the nearby field for defecation in the mornings and at night. This was more difficult for people who were physically disabled due to leprosy. Unsanitary and dirty neighbourhoods are an ideal breeding ground for leprosy bacteria⁴.

Case study 5

“I am Kassa Wodimagegn. I am 64 years old. I came here from Gonder in order to get proper medical care at ALERT. I came to this place 20 years ago. Before the project, just like the whole community, we used to go to the nearby jungle to defecate. As a disabled person, this was more dangerous and uncomfortable for me. We usually fell in the dark and were attacked by ants and

⁴ Leprosy Mission (2013)



other insects. Worse, I was robbed by thieves at night, who stole my clothes and the money I had earned from begging. I got back home almost naked. Now the toilet is close to our house and accessible to us. We are very much grateful for the project in so many ways!”

Case study 6



“I am Muliye Kassa. I am 72 years old. I left my birth place 25 years ago to get medical assistance at ALERT hospital, which was the only centre for people affected by leprosy. I was affected by leprosy long ago. I got the treatment on time and I was well. Before recovering fully, I started to work as a mason in an urban slum area. This job requires frequent contact with mud, soil and dirt. After

working for some time, I felt the disease was aggravated, and I was re-admitted to the hospital. Later on, both my legs were amputated. The project is improving my situation as now I can get water for caring for and treating my body.”

Addressing inequalities and creation of awareness on disability

In Ethiopia, as in other developing countries, there is very little understanding of leprosy. As a result, the disease is surrounded by various myths, superstition and stigma. Many think that leprosy is a punishment for something evil, and hereditary. An example is the misconception that leprosy is the worst of all disabilities, seen in the phrase ‘tiliku beshita’, meaning ‘the great disease’. This is aggravated by a number of sayings that degrade people affected by leprosy, for instance, ‘Komatan komata kalalut gebiche lifetfit maletun aytewum’, meaning ‘If you don’t tell a leper that he is leper, he dares to eat with you’, and ‘Yezarews bird komata yasadakifal’, meaning ‘Today’s chilly weather forces you even to hug a leper’.

The WaterAid Ethiopia project uses community and government meetings and the media to raise public awareness about causes of disability in order to correct misperceptions. The project also fully engages people with disabilities from inception to evaluation, and includes reporting at each phase to ensure the voices of affected people are heard every step of the way. The project also ensures people with disabilities get priority in participating in WASH management committees and other income-generating activities, in order to challenge the existing

misconception by the general public that people with disabilities are not fit or productive citizens and are dependent upon society.

Case study 7



“My Name is Lomi Baye. I am 33 years old and a mother of four. I came from one of the rural areas, searching for a better life. I am a disabled woman with one of my legs impaired. Just like everyone else, I contributed to the project as much as I could. After construction, I was elected by the community as secretary of this project. My roles and responsibilities include managing the water point and the latrine to ensure proper use,

collecting fees from the community for maintenance, fencing and other matters, and saving the remaining funds in our account. My active participation has helped me economically – I earn some money from the project to support my family – and socially – the project has helped challenge social attitudes towards the disabled. Having this experience has encouraged me to continue my schooling, to join other local associations like the district health and sport associations, and also to become a member of a political party. I regret the time I have spent begging.”

Future actions

The WASH sector has limited knowledge of neglected tropical diseases (NTDs) such as leprosy, and it is important to address this by conducting further studies on the links between NTDs/ leprosy and WASH, to inform appropriate action and improve cross-sectoral collaboration. The long-term solution to NTDs like leprosy requires improvement in hygiene and sanitation practices; therefore, it is crucial to create integrated approaches to disease prevention, control and management that include aspects of both WASH and NTD programming. Incorporating WASH in an integrated package of essential primary healthcare services, available to the entire population, will also be useful to assist healthcare and treatment for people affected by leprosy and other NTDs, as well as to improve overall population health.

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Photos: WaterAid Ethiopia



WaterAid transforms lives by improving access to safe water, hygiene and sanitation in the world's poorest communities. We work with local partners and influence decision-makers to maximise our impact.