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### ACCESS TO SANITATION AND SAFE WATER: GLOBAL PARTNERSHIPS AND LOCAL ACTIONS

## Equal access for all?: Issues for people with HIV and with disabilities in Ethiopia

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*This paper challenges the assumption that once water and sanitation facilities are provided, everyone in the community has access to them. Drawing on detailed case studies from Ethiopia, the paper shows how two groups with critical needs for safe water and sanitation: those with HIV (PLWHA) and those with physical disabilities (PWDs), face severe access constraints. Findings revealed that both groups need more water, and need latrines more than others, yet their access to available facilities is restricted. PLWHA need more water and latrines due to vulnerability to and treatment of symptomatic infections, but face discrimination in access. PWDs need more water and latrines due to increased exposure to dirt from crawling, and increased vulnerability to the dangers of open defecation, but physical limitations and inappropriate designs limit their access. Since the underlying causes of their access constraints are different, separate programming and policy solutions are required for each group.*

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### Background and rationale

Water and sanitation coverage in Ethiopia is among the lowest in the world, with an estimated 52.5 % of the population having access to improved drinking water and only 37.2% to adequate sanitation. Figures for the urban sector were 82% for improved water and 86% for adequate sanitation, while the corresponding figures for the rural sector were 46.5% and 28% (Ministry of Water Resources 2007). Progress has been made in some regions since 2005, notably in Southern Nation and Nationalities Peoples Regional State (SNNPR), but updated national statistics are not yet available. Given the extremely low coverage, the temptation is to aim for rapid scaling up of infrastructure to achieve mass coverage. But this paper argues that unless the access constraints of different groups within the community are addressed, coverage will be overestimated. Simple policy solutions aimed at 'vulnerable groups' in general will also fail to achieve the goal of universal coverage unless the different constraints of each group are addressed. For example, while some face economic constraints, unable to afford sufficient water for health, others such as the homeless or people with HIV may be denied access by the community, while people with disabilities, the sick or the elderly may be physically unable to access facilities.

All of these groups have the same rights to water and sanitation as others and it is the responsibility of governments and communities to fulfil these rights and to undertake the planning and investment necessary to do so. Furthermore, exclusion of any group from water and sanitation access puts the entire community at increased risk through the spread of disease, and this in turn has consequences for the local economy. This contrasts with discrimination in other areas such as education or employment, where exclusion of some groups may increase opportunities for others.

Finally, if constraints in physical access are not addressed from the start, they may impose far higher costs in future, when existing infrastructure needs to be adapted (Jones and Reed, 2005). In conclusion, addressing the different access needs of groups within the community not only addresses their human rights, it is also in the interests of the community and the national economy.

### Why did WaterAid Ethiopia select PLWHA and PWDs?

WaterAid aims to improve access to domestic water and sanitation for the world's poorest. As part of its efforts to strengthen its pro-poor, inclusive approach, WaterAid Ethiopia selected two groups with special needs in water and sanitation for an action research program (see full reports Magrath and Tesfu, 2006; Tesfu and Magrath, 2007). People with HIV/AIDS and people with disabilities were selected because:

- Disability and HIV are strongly linked with poverty in developing countries (DFID, 2002; Hsu, 2003);
- They are more vulnerable than others to the health impacts of inadequate water and sanitation due to their physical condition (Mamo and Frazer, 2004);
- They are neglected and discriminated against within the community (Tirussew, 2005; ICWR, 2003);
- There is very limited information about WATSAN needs and constraints of these groups in Ethiopia and internationally but it is thought that
- Their equal rights to water and sanitation facilities are not being met;
- Although reliable data is limited, especially for people with disabilities (Tirussew, 2005), both groups are likely to be significant in many communities in Ethiopia.

Both groups are diverse, with needs depending on the stage of progression of HIV and the type of disability, as well as on socio-economic status and rural or urban location. Other groups with access constraints in Ethiopia include the homeless, the elderly, the sick, pregnant women and children. However, not all of the above conditions apply for these groups. On the other hand, they are likely to benefit from efforts to improve access for PLWHA and PWDs.

## Methodology

### Site selection

The two studies were conducted in different sites. Addis Ababa was selected for exploring HIV-WATSAN linkages because a key WaterAid partner Zema Sef, runs both a WATSAN project and an HIV support project in Lideta Sub-City. Similarly, Butajira was chosen for the disability research because Zema Sef has a WATSAN project and a disability support project there.

### Research tools and sampling

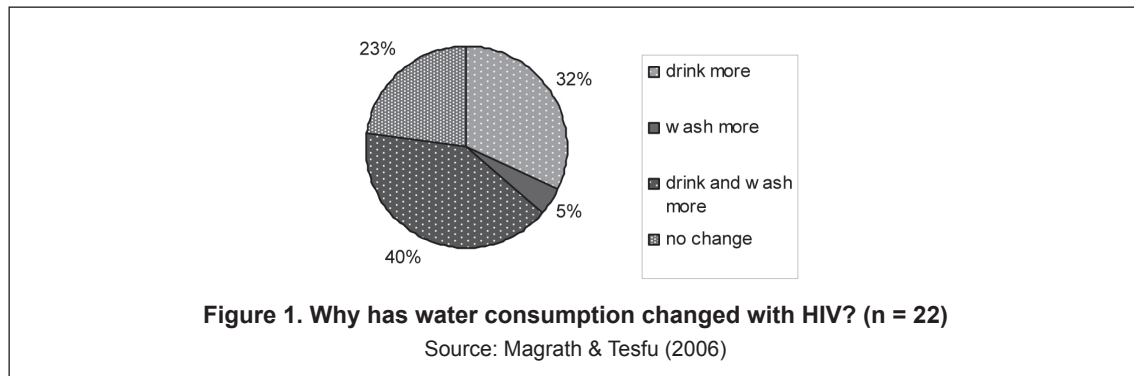
The main data collection tools for both studies were in-depth interviews and focus group discussions. These were supported with key informant interviews, village profiles, direct observation and secondary data collection. Both studies used a purposive and a control sample. For the study exploring linkages between HIV/AIDS and WATSAN (the HIV study), 22 affected and 20 unaffected respondents were interviewed, while 22 people from both categories participated in focus group discussions. For the study investigating links between disability and WATSAN (the disability study), 32 affected respondents were interviewed and 51 disabled and non affected respondents participated in focus group discussions.

For the HIV study respondents were drawn from a range of wealth groups and water and sanitation access situations, as well as covering different stages of HIV infection and sickness. Adult women and men were interviewed but no children. For the disability study respondents were restricted to those with motor disabilities which limit physical access to WATSAN facilities. Other variables included urban and rural residence, and those with or without some kind of NGO support. Men, women and children were included in this study.

## Main findings

### Need for water

Both PWDs and PLWHAs need **more water** than the rest of the community. Over three quarters of the HIV positive interview respondents said their needs for water for drinking, bathing and washing, had increased since they tested positive for HIV, especially during the symptomatic phase (see Figure 1). In three cases the increase amounted to a doubling of consumption, and seven respondents needed to buy more water as a result of their increased need. Common sicknesses for PLWHA which increase water consumption include skin



infection, fever and diarrhoea. Water is also used to wash household items and bedding, and for frequent bathing to protect PLWHA from sickness. Those taking anti-retroviral treatment (ART) need to drink more water to reduce side effects. Abundant clean water is also essential for PLWHA care-givers as it helps to protect them from the virus.

People with disabilities need more water for washing and bathing because of frequent falls due to loss of balance, particularly when travelling in the rain and on rough roads. Crawling and squatting exposes them to dirty materials, especially when entering toilets shared by many people. Using their hands for support in the toilet also brings them into contact with urine and faeces. Mobility equipment causes sweating and can blow dust.

**Demand for latrines**

PLWHA need latrines nearby due to frequent diarrhoea, experienced by two thirds of HIV positive respondents, most of whom use latrines shared by many people.

**Box 1: Increased demand for latrines**

Bereket is HIV positive, and lives in a local government rented house, where he shares a communal latrine. He has frequent diarrhoea which does not respond to medication, but he always has to queue for a long time to use the toilet.

Abeba also suffers from frequent diarrhoea, but the nearest public toilet is 6 minutes walk away. It is also dirty, with 30 households sharing the same toilet. So she uses a potty in the house, which her husband and children then take to the latrine.

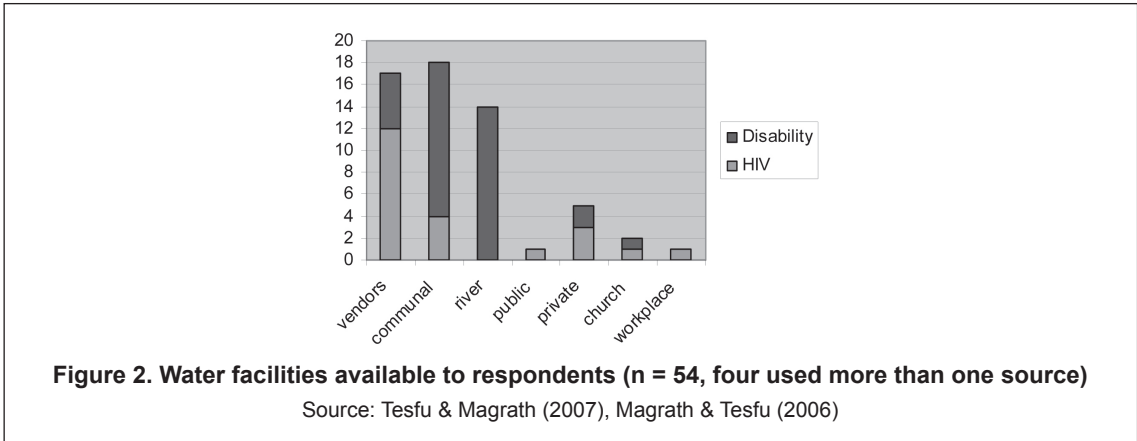
PWDs need latrines more than others since open defecation is tiring and dangerous, especially at night, due to the risk of falling, and exposure to dirt and to wild animals, such as hyena. But if they use locations closer to home during daylight hours, there is no privacy. Women PWDs are particularly vulnerable to sexual harassment as they cannot move away from a situation quickly. Despite such difficulties, respondents did not wish to be accompanied, preferring to be independent.

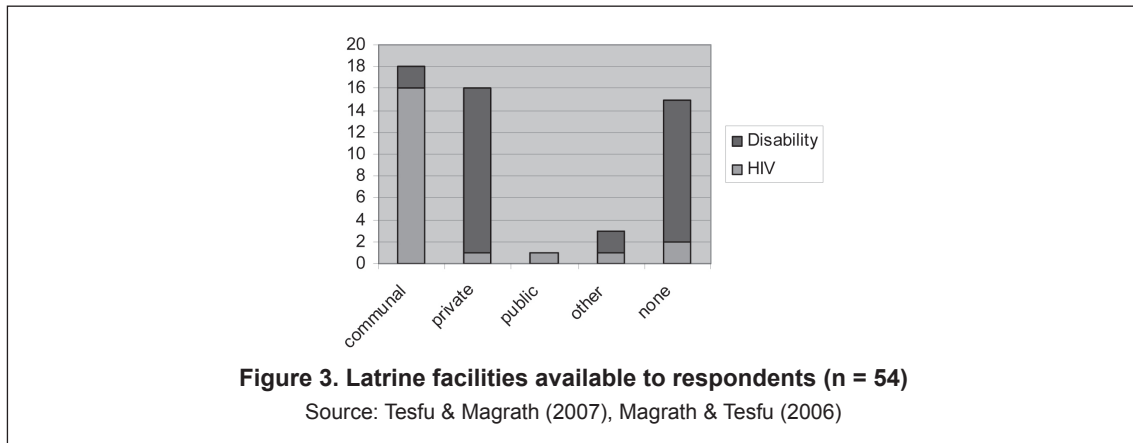
**Access to water and sanitation**

*Availability of facilities*

Most respondents from both studies use shared facilities, due to poverty and limited availability. The majority of PLWHA respondents, along with other poorer residents of Addis Ababa, do not have their own private water connection. They get water from expensive private vendors, or communal water points. The communal points are cheaper but often further from home, with restricted opening times, so some respondents had switched to vendors on becoming sick. The disabled respondents living in semi-urban or rural locations access water from communal water points and dirty rivers (see Figure 2).

Most of the HIV respondents living in Addis Ababa had access to a communal toilet, used by up to 40 households, but only two had no toilet access at all. By contrast, less than half of the respondents with dis-





abilities, who live in a small town and the surrounding rural area, have access to a toilet (Figure 3). If they do have a toilet, then it is usually in their house compound. In both locations latrines are poorly maintained, which increases the risk of sickness.

**Constraints on access**

In spite of their increased need for water and sanitation, access to available facilities is restricted for both groups, compared with the rest of the population, although the reasons are very different in each case.

PLWHA have restricted access due to discrimination and sickness. Although some PWDs experience mild harassment, discrimination against PLWHA is more extreme and more prevalent. By contrast, PWDs have limited WATSAN access due to physical limitations and inappropriate design of facilities. These limitations vary depending on the type of mobility equipment (if any) and the type of facilities used. Sick or bedridden people with HIV/AIDS also experience physical limitations which limit access to water and sanitation facilities. From our sample of 22, five found it harder to get water and three to use the latrine because of sickness.

*Discrimination in access*

The main constraint on PLWHA using available WATSAN facilities is discrimination, personally experienced by over one third of HIV positive respondents. Discrimination in water use is experienced in collection from the tap, use of receptacles, washing of clothes and locking of the bathroom. But the most extreme forms of discrimination occur in latrine use. Surprisingly, people experience discrimination in private as well as rented accommodation, and from close family members as well as from neighbours. People with disabilities experience mild harassment when using a toilet because it takes them longer than others.

**Box 2: Discrimination and harassment in latrine use**

I am divorced and live with my 11 year old daughter. We used to rent a house, but I couldn't bear the various forms of discrimination from my landlord. They suspected me of the HIV virus when I started to visit the latrine frequently. Then they locked me out of the toilet and the water tap. They even went to the extent of washing the ground where I walked to the toilet, and made me pay extra money for the water I was using.

My Name is Misbah; I used to face harassment in toilet usage. The toilet was designed for people with no disability and therefore was not appropriate for people like me. It took me longer to use the toilet and to handle my clothing before and after defecation. During this time people who wanted to use the toilet become impatient and made unnecessary comments. They used to say 'are you sleeping in there or what?' and some times "did you contract the toilet just for yourself?'. I couldn't bear all this harassment and housing problems in Addis so I moved to Butajira where I was born.

**Box 3: Discrimination in water use**

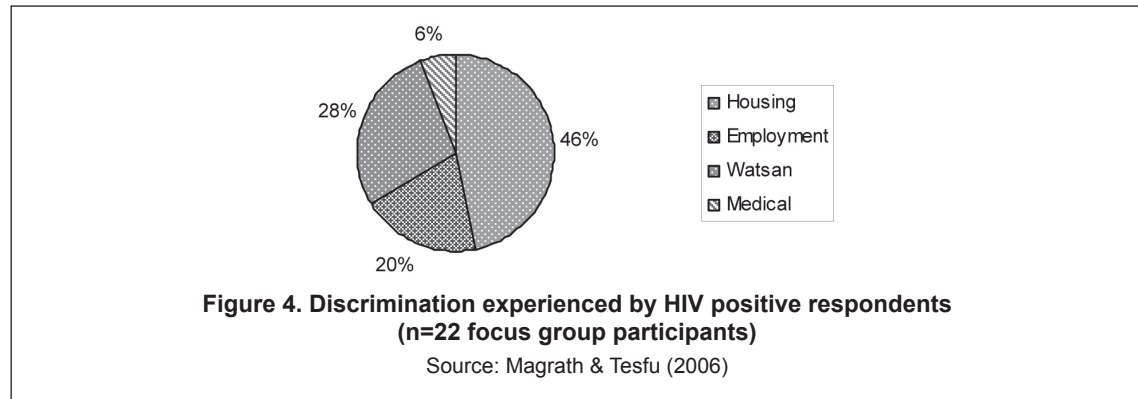
Meriam is living with HIV. She washed her clothes and hung them outside in the sun, but later found them strewn about on the dirty ground. Next time, she waited outside until the clothes dried. The neighbours reacted by not hanging their clothes on the same washing line, afraid that the virus might be transmitted through it.

For both PLWHA and PWDs, discrimination in WATSAN use is part of a complex web of discrimination affecting housing, employment, social life, and political participation. Discrimination is often based on misconceptions about how the condition is acquired or transmitted and about the person’s capabilities. PLWHA are shunned because of the association of HIV with sinful or inappropriate behaviour, and the fear of contracting the virus through any form of contact. Discrimination is so pervasive that it causes PLWHA to hide their status, which in turn limits their access to health facilities and medication, including ART. Disability is also associated with sinful behaviour on the part of the parents, on devil spirits or curses (Tirussew, 2005, Tesfu and Magrath, 2007). But PWDs are more often marginalized because they are believed to be incapable, useless and dependent.

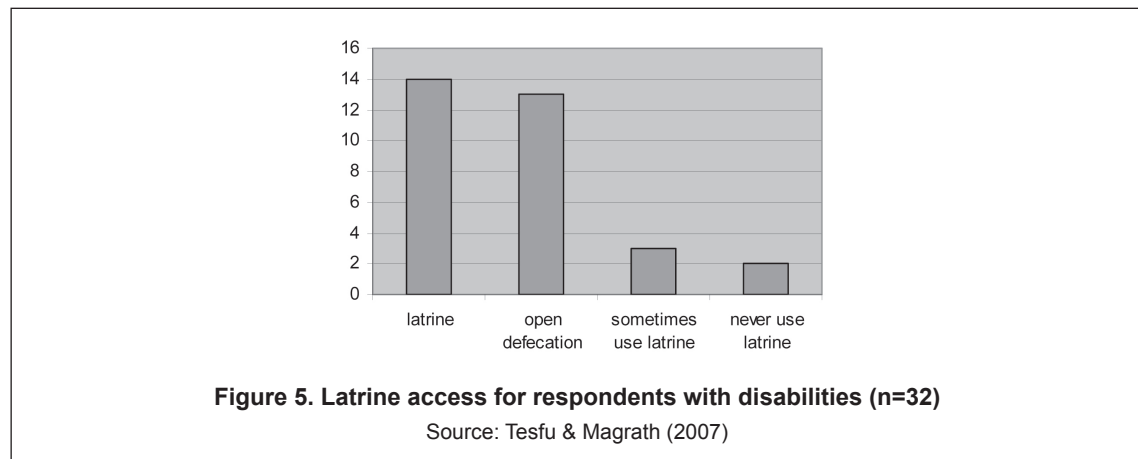
Despite the evidence from research respondents, unaffected members of the community denied any awareness of discrimination against PLWHA in their neighbourhood, although discrimination against PWDs was acknowledged. This reflects the fact that HIV remains a taboo topic.

*Physical restrictions on access*

The main constraints on PWDs accessing WATSAN facilities are physical limitations and inappropriate designs. PWDs cannot collect water by themselves because their hands are used for mobility, mobility equipment rarely accommodates carrying of containers, and many use shared water sources (communal taps or rivers) which tend to be far from their homes. As a result, they are forced to depend on care-givers for water collection. Even the few with a private connection find the tap too high and difficult to use. Tap design is also an issue for bed ridden PLWHA.



About half of the PWD respondents have access to a latrine, but find them difficult or impossible to use, because of inappropriate designs (see photos 1, 2, and 3 below). Five respondents resort to open defecation or using a potty, even though the family have a latrine in the house compound (see Figure 5). Most pit latrines have wooden floors, which are slippery when wet, difficult to clean, and have gaps in which crutches get stuck. Some have raised entrances inaccessible to wheelchairs (photo 2) or raised latrine blocks (photo 3) all of which reduce access. Paths to the latrine are often hazardous, muddy and slippery. Household latrines may be of poor quality, old or rotten, and mobility equipment can be heavy increasing the fears of disabled





people that the latrine may collapse under them. Children with disabilities also fear falling into poorly constructed latrines.

**Box 4: Inappropriate design limits access**

My name is Aleka Giber. I am 18 years old. I moved to Butajira from a rural location to get an education. Now I'm living in rented accommodation. I get water from vendors via my caregiver. I can't collect water myself because I can't carry it, and anyway, the tap is too high up for me to reach from my wheelchair. The latrine is also very difficult for me to use, as my wheelchair cannot get up the step at the entrance. So I have to get off the wheel chair and squat. Even squatting, it is very difficult for me to enter the toilet, and the raised latrine slabs are also awkward for me. The latrine is very dirty, as it is shared by the landlord's family and other people who rent rooms here. My body and clothes rub against the dirt. I feel that in order to solve this problem we need to have facilities according to our types of disabilities.

**Which is more difficult to access: water or latrines?**

PLWHA and PWDs have different views on which facilities are more difficult to access. For PLWHA latrine use is more of a problem than water. They claim that discrimination is much worse in latrine use because people believe that a latrine can easily transfer the virus from a sick person to a healthy one.

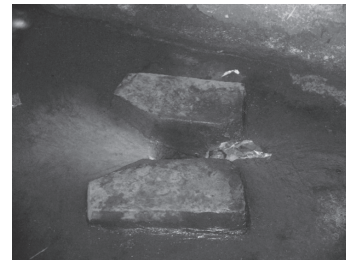
By contrast, most PWDs (23 out of 32 interview respondents) said collecting water was more of a problem for them than accessing latrines. This is a surprising result, given the obvious difficulties that disabled people face in open defecation and latrine use, and the implications for hygiene and general wellbeing. They explained that they have to rely on their care-givers to collect water and this makes them feel dependent. Dependence on others limits the quantity of water the disabled feel they can use without overburdening the care-giver. By contrast, nearly all respondents could use the latrine alone.



**Photograph 1. Inappropriate latrine design (raised entrance)**



**Photograph 2. Inappropriate latrine design (raised entrance)**



**Photograph 3. Inappropriate design (raised footplates)**

**Women and WATSAN**

Access to clean water and safe latrines is particularly important for women because of their gender roles within the household as well as their personal needs (UN-Water 2005; UN DESA DAW, 2005). In Ethiopia, as elsewhere, water collection, clothes washing and cooking are mainly the responsibility of women. This means that they use more water than other household members. Because of their role in food preparation for the whole family, good hygiene is also critically important and requires clean latrines, as well as an adequate water supply. Women need extra water during menstruation and they need privacy during defecation due to their greater vulnerability to sexual harassment.

Incidence of HIV/AIDS in Ethiopia is higher for women than for men (Federal Ministry of Health, 2004), and this is reflected in our research sample, where three quarters of interview respondents are women. Women are not only more susceptible to HIV, but also reach the symptomatic phase of high water demand faster than do men. Furthermore, since it is women who fetch water they are more exposed to discrimination at the water taps than are men. Most care-givers are women, and they need extra water to protect themselves from infection. In focus group discussions, women ranked problems with water access higher than did men.

Women with disabilities need more water than men with disabilities in order to fulfil their household responsibilities. Though they are disabled most of our women informants wash clothes, and cook in a sitting position, once the water has been collected by another household member. Women with disabilities are especially vulnerable to sexual harassment during open defecation, as they cannot move quickly, and this increases their need for household latrines.

### **Lack of coping mechanisms: latrines and water points**

One of the most surprising results of the research was the stark lack of coping mechanisms in WATSAN access both for PLWHA and for PWDs. Neither the affected individuals nor their families seemed to be making much effort to accommodate their special needs. This reflects not only a lack of ideas and technical knowledge but also the marginalization of these groups within the society.

PLWHA seem to cope with discrimination by moving to new accommodation, using facilities at night, using public facilities, for example in restaurants, or using facilities at their workplace. A few have initiated legal action against landlords or neighbors on grounds of discrimination. Only two PWD respondents had attempted to change the design of their latrines.

### **Box 5: Coping mechanisms**



**Photograph 4. Separate pit latrine as a coping mechanism**

One elderly physically disabled respondent had made himself a defecation chair, but it is now broken, so he uses a potty. In another family a separate, shallow pit latrine was built for a ten year old disabled boy, who feared falling into the poorly constructed family latrine (see photograph 4). Several other respondents with a family latrine use potties or open defecation because they cannot use the latrine.

## **Conclusions**

The main conclusion from the research is that **PLWHA and PWDs need better access to water and sanitation** facilities, as a matter of urgency. The current situation, reflected in the case studies presented, causes needless suffering and violates the human rights of those affected. Addressing their needs will yield public health benefits for the whole community. But while both groups feel the need for facilities closer to their homes, and ideally private facilities within their homes, they recognize the economic and logistical constraints on achieving this. Neither group favoured separate communal facilities, fearing that this would increase discrimination and exclusion.

The second conclusion is that although both groups experience increased needs and reduced access, the underlying causes of their access constraints are different and therefore different programming and policy solutions are required. PLWHA themselves stressed that **tackling discrimination** in the community was at least as important as provision of physical facilities. By contrast, PWDs stressed **appropriate accessible designs** as the priority, and had a number of specific suggestions including use of cement instead of wood in latrine construction and lowering the height of taps. However, there was a limited range of ideas for technical improvements, suggesting that outside technical input, adapted to local conditions would be required for the development of successful inclusive designs.

Thirdly, **marginalisation** within the community is a major reason why the needs of these groups are not being met. This means that attitudes at the community level need to be addressed in any attempt to meet the practical needs of these groups. Although an outside stimulus may be required to raise the profile of taboo topics such as HIV or disability, and to provide medical information to dispel misconceptions, in the end the community or neighbourhood must take responsibility for tackling these issues in locally appropriate ways. Increased involvement of PLWHA and PWDs in decision making and employment is likely to have a big impact not only in raising their profile but also in developing successful solutions.

Finally, national policy solutions based on blanket remedies for ‘vulnerable groups’ are unlikely to meet the varied needs of everyone in the community. Further research and improved data collection is required. But perhaps even more important, members of the targeted groups should be directly involved in policy formulation to ensure that their needs are met. (Magrath and Tesfu, 2007).

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