

Water, sanitation and hygiene for arresting opportunistic infections for people living with HIV and AIDS

Living with HIV & AIDS

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CREATE and WaterAid in India

Towards Inclusive WASH Sharing evidence and experience from the field



Background

WaterAid's equity and inclusion framework provides a mandate for the country program to prioritise the water, sanitation and hygiene (WASH) needs of socially excluded and discriminated people. People living with HIV and AIDS (PLHA) are frequently discriminated against in every sphere of life and often excluded from mainstream society. Uttar Pradesh (UP), the most populous state of India, is considered highly vulnerable to HIV and AIDS due to its low level of literacy, high level of poverty and large migrant population. UP has so far recorded low HIV and AIDS prevalence, but occurrence has been reported at an increasing rate over recent years. Restricted access to clean drinking water, safe sanitation facilities and adequate hygiene services, due to various social, educational and economic factors, increase PLHA's vulnerability to opportunistic infections, such as diarrhoeal disease, and reduced life expectancy.

Through this project, WaterAid in India (WAI), working with local partner CREATE, has sought to reduce barriers for improved access to sustainable WASH for PLHA by supporting locally appropriate, practical and effective solutions.

Location

» Uttar Pradesh, India



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Initial situation

In India, HIV and AIDS remains a sensitive issue because it links directly to issues of sexuality, sexual choice and sexual health, topics which are still considered as taboo. Stigma against HIV and AIDS is a hidden epidemic that is as large as, or even larger than, the HIV epidemic itself. PLHIV face different types of discrimination that affect their housing, employment, social interactions, childcare and access to medical services, water and sanitation. Absence of awareness of transmission paths coupled with their family's prejudices, means PLHIV are frequently barred from using toilets and common water pots at home or accessing their community's common water points. With already failing health, they have to walk greater distances to access water sources and also open defecation sites.

The likely consequences of inadequate access to WASH for PLHA were not being explicitly identified and integrated into either HIV and AIDS interventions or WASH sector programs in India. The importance of WASH has been neglected even in the support systems created for the institutional and clinical care for HIV positive people at the local, state and national level. Guidelines and training manuals developed by India's National AIDS Control Organisation (NACO) and the UP State AIDS Control Society do not have adequate focus on appropriate WASH practices for the reduction of opportunistic infections. Anti-Retroviral Therapy (ART) centres, Community Care Centres and District Level Network centres under the programming of NACO and the UP State AIDS Control Society provide medical and institutional care to identified HIV patients, but have not previously incorporated WASH into risk prevention messaging. Drop-in centres also play a considerable role in supporting HIV and AIDS patients. Even these institutional set ups are often lacking in basic WASH facilities such as a latrine or safe drinking water.

Figure 1
WASH corner set up in a
Community Care Centre,
Lucknow, India
J Jaiseelan, WaterAid in India



Program approach

This program was developed in collaboration with the UP State AIDS Control Society and the state level network of people living with HIV and AIDS.

The program has a vast geographical coverage of 14 districts across UP. In each district three delivery points were identified namely, (i) the ART unit at the respective district medical college or hospital; (ii) Community Care Centres and; (iii) the District Level Networks. Other stakeholders who were involved in the program include water supply bodies, the UP State AIDS Control Society, Panchayat Raj Department¹ and other agencies working on HIV and AIDS. The program was designed to serve the community through service delivery and advocacy with the community and stakeholders.

To ensure that the project design and interventions were supported by evidence from research and surveys, this program started with a situation assessment and discrimination study covering:

- a. Existing knowledge, attitudes and practice of PLHA vis-à-vis WASH in daily behaviour; and
- b. Coping strategies amongst PLHA for opportunistic infections and WASH infrastructure and facilities available to them.

Based on this study, interventions were planned to provide more facilities for PLHA and reach out to the community regarding WASH benefits. The main activities were to:

1. Develop learning products and information, education and communication (IEC) materials to build awareness of WASH among PLHA, including games and posters;
2. Provide access to safe drinking water and sanitation at locations of regular clinical/treatment visits;
3. Educate all clients who visit care and support institutions by including WASH in risk prevention messages;
4. Establish WASH corners to promote low-cost WASH resources and solutions for PLHA and their carers;
5. Advocate at community and government level on PLHA's rights to WASH and the importance for universal access.

One objective of the program was to increase understanding of and access to WASH, by providing WASH information and resources through **WASH corners** at locations where PLHA were already receiving clinical care, support or treatment. These WASH corners featured low-cost items including different types of water disinfectants, oral rehydration salts (ORS), safe drinking water, soaps and sanitary napkins (Figure 1). Model toilets were displayed at all locations to impress the need for home-based sanitation facilities.

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¹ The panchayat raj is a South Asian political system of governance at the local level.

The program also aimed to improve understanding among the health, HIV and AIDS and WASH sectors, of the benefits of promoting WASH as a risk prevention measure for opportunistic infections among PLHA and their carers. Program staff worked with clinic staff, visitors and their families to **disseminate knowledge** of opportunistic infections, diarrhoea management, safe drinking water, low-cost latrines and hygiene. Interesting WASH-related illustrations, IEC handbills and posters were printed on eight different WASH issues including correct hand washing practice, safe water handling, diarrhoea management and toilet construction. Having pictorial illustrations proved very effective in transmitting messages to clients on safe drinking water, sanitation and hygiene related issues. Interesting games were also designed to put forth messages through a joyful learning process.

In order to measure behaviour change over a period of time, **WASH kits** that included water bottles with water disinfectants and ORS packets were distributed through the centres (Figure 2). Monitoring data collected on subsequent visits to the ART centres showed that many recipients of these kits now carried drinking water with them when they visited the centres. In informal discussions, participants revealed that since receiving WASH information and kits they had begun to carry safe water with them whenever travelling away from home.

Figure 2
Hygiene kit provided to PLHA through support centres in Uttar Pradesh, India
Mr Sanjay, CREATE



Friendship group meetings were scheduled to raise awareness of safe drinking water, sanitation and hygiene. Discussions in these groups focussed on encouraging toilet construction, hand washing and making oral rehydration salts. Program staff also supported selected families to gain access to **household latrine construction** services provisioned under the project and guided others to access government incentives for construction of household toilets. As the program matured, the pressure to reach out more to the community was inevitable. Participants were encouraged to participate in activities on larger scales and an effort was made to address these groups on WASH and its benefits.

Consultation meetings and workshops were arranged with government ministries and departments, nodal agencies and networks and organisations working with PLHA on their rights to water and sanitation and the gap in existing policies and programs. These initiatives further supported NGOs working on HIV and AIDS and networks of PLHA, to establish linkages with WASH sector institutions and agencies. The program also spearheaded the state level campaign 'Right to Safe Drinking Water and Sanitation' with support from various NGOs as part of WaterAid's wider advocacy campaign.

Impact

The direct link established between WASH and opportunistic infections through this program was well received by the UP State AIDS Control Society. As a result, WaterAid in India joined a partnership to promote the idea to a much larger audience through the Red Ribbon Express campaign, a unique HIV and AIDS awareness intervention of NACO (see Box 1). Since this program began, the Panchayati Raj Department has since announced its intention to provide toilets and hand pumps to all PLHA deprived of such facilities.

Monitoring showed widespread behaviour change among many PLHA who encountered this program—including a tendency to carry safe drinking water practice regularly hand washing at critical times and use of toilets.

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BOX 1 All Aboard! The Red Ribbon Express Campaign in Uttar Pradesh

The Red Ribbon Express (RRE) is a national advocacy campaign designed to raise awareness of HIV and AIDS. A specially designed eight coach train travelled over 25,000 kilometres across 24 states and stopped at more than

152 stations. At each station, the train stopped for two to three days and hosted both on-platform and off-site communication activities with the public and the media around HIV awareness and stigma reduction. This campaign was developed by NACO in partnership with various government departments and national and international NGOs.

WaterAid in India joined the second phase of a RRE project to spread its messages on WASH and create awareness on the importance of WASH in arresting opportunistic infection for people living with HIV and AIDS. WaterAid met the arrival of the RRE in seven stations across UP and set up interactive exhibition stalls to spread WASH messages through folk songs and street dramas (Figure 3). During this initiative WaterAid in India put up 2,500 banners, 25,000 posters and set up 20 stalls. WaterAid in India's partnership with the RRE campaign in Uttar Pradesh was highly successful at reaching a very large audience with messages about WASH and HIV.

Figure 3 Interactive stall set up during the Red Ribbon Express campaign at Lucknow railway station, India J Jaiseelan, WaterAid in India



The increase of WASH awareness in PLHA over the course of the program has resulted in healthier and more informed PLHA, which has had a direct influence on the frequency and severity of opportunistic infections and their quality of life (Box 2). This could be backed by evidence of data recorded during an impact study. The impact study was conducted in six district's ART centres with a sample size of 144 PLHA who had participated in the program. Some of the benefits recorded are:

1. Toilet usage increased from 10% to 55% at family level;
2. The percentage of families where all members used toilets increased from 43% to 82%;
3. Around 85% of participants did not report incidences of diarrhoea in the past 6 months;
4. Almost all respondents now used one of the disinfectants to purify their drinking water; and
5. Knowledge and awareness of hygiene practices (hand washing at critical times) increased from 52% to 95%.

Working simultaneously with institutions set up by government departments (NACO and UPSACS), WASH sector NGOs and various care and support centres established for PLHA made it possible for WaterAid in India and its local partner CREATE to have a lasting and widespread impact. CREATE's previous expertise working with people with HIV and AIDS was critical to the success of the program design and implementation.

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BOX 2 The Story of Poonam

Poonam (Figure 4) is a 30-year-old lady who was forced from her home when her family discovered she had AIDS. Poonam now shares WASH knowledge with clients visiting her local Community Care Centre.

She says:

I have seen a constant increase in the CD4² counts of many clients to whom I work with. Those who have observed regular hygiene practices of hand washing at critical times and drinking safe water are much healthier than before. Being from this community and helping those like me gives me immense pleasure. I will always keep guiding my fellow brothers and sisters about WASH because it is such a simple way to keep healthy.

Figure 4 Poonam orienting a client on WASH in her Community Care Centre, India Mr Sanjay, CREATE



² CD4 cells initiate the body's response to infections. The number of CD4 cells circulating in the blood gives an indication of how well a person's immune system is functioning.

Learning and challenges

PLHA are often compelled to hide their HIV and AIDS status from their family and community for fear of being evicted from their home. PLHA and their families may face discrimination and social stigma. This situation reinforces the culture of silence around HIV and AIDS and makes it hard to quantify discrimination.

Reaching out to people in a way that is sensitive to their right to privacy, including those who had not revealed their HIV and AIDS status in the first instance, still remains a challenge for the government agencies and other service providers. Delivering

WASH services through ART centres is preferable to working at the household level, which runs the risk of revealing a person's HIV status to the whole village in breach of the confidentiality clause of HIV and AIDS programming. Therefore, a key innovation of this program is that WASH messages and resources are delivered through centres rather than at household level.

PLHA need special provisions in key water and sanitation sector programs to enable them access without compromising their health status. At present there are no such schemes prioritising services to them. As a result of advocacy initiatives under the program, WaterAid was able to get approval from the State Rural Development Minister for special water and sanitation facilities for PLHA families. These sorts of targeted service delivery programs should be designed with care to ensure the confidentiality clause of HIV and AIDS programming is upheld.

The program has successfully demonstrated the link between WASH accessibility and the reduction of opportunistic infections and has influenced the key sector players to ensure provision of such facilities in all its institutional and clinical care units across UP state. Water Aid India has since initiated dialogue with NACO to promote WASH in their program design and services.

References

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- » CREATE (2010) *Barriers to access to water, sanitation and hygiene for people living with HIV and AIDS*

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