

The Living with Dignity Program in Papua New Guinea

Living with HIV & AIDS

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Towards Inclusive WASH Sharing evidence and experience from the field



"We wanted to use a participatory approach to designing our technologies"

Steve Layton

Background

Appropriate Technology (AT) projects works in partnership with a number of front line community organisations, including the National AIDS Council (NAC), and people living with HIV on different practical and technical WASH solutions for people affected by HIV (encompassing family members and dependants of a person living with HIV) in Papua New Guinea (PNG). While many non-government organisations (NGO) concentrate on awareness raising and counselling of people with HIV, ATprojects provide practical technology assistance which addresses the individual and environmental barriers to water, sanitation and hygiene (WASH) encountered by people affected by HIV and AIDS.

Figure 1

Participants interact with different tools in the personal hygiene kit as part of the design and refinement process, PNG

ATprojects



Location

» Eastern Highlands Province, PNG



In 2002, ATprojects was approached by the NAC to research, identify and develop a suite of practical home care solutions that would address the WASH barriers faced by people living with HIV and their caregivers. These solutions currently include a personal hygiene kit and portable rainwater catchment.

Approach taken

Through detailed discussions with people living with HIV (PLHIV) and their carers, ATprojects have developed a considerable knowledge base on the situation of people affected by HIV in resource-poor settings in PNG (see Box 1). One of the ongoing lessons learnt is that simple, practical tools are effective and useful to manage this group's special WASH needs and that the end-users must be involved in the tool design from the outset.

Originally the program had planned to gather input from PLHIV as the potential end-users of the tools through responses to proposed questionnaires. However, it became clear that it would be necessary to build relationships with communities before any information would be shared or accurate information gathered by questionnaire. Relationship building was as much about gaining the trust of participants as well as articulating WASH barriers.

“Our project wanted to use a participatory approach, but it was often difficult for the positive people and their carers to see a possible solution to a problem when the problem itself was not yet recognised.”

Steve Layton, Co-Director ATprojects

During these initial awareness raising and relationship building exercises, the ATprojects team members gathered far more and detailed information than the questionnaire alone could ever have produced.

As part of the participatory design process, ATprojects invited people affected by HIV to discuss their WASH needs and develop possible solutions together in a workshop. The workshops emphasise a ‘touch, feel, smell’ approach¹ – where participants have the opportunity to interact with and develop possible technological solutions to be included in the Living with Dignity kit (Figure 1). This approach of using working examples of tools from the project has acted as the catalyst for developing future kits – stimulating additional thoughts and ideas that might otherwise not have been considered. For example, towards the end

¹ For more information on the ‘touch, feel and smell’ approach – please see the *Living with Dignity* video. This video is available on the Inclusive WASH CD and at www.inclusivewash.org.au/case-studies

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Figure 2
Miriam Layton, Co-Director
of ATprojects, with the
personal hygiene kit,
including portable shower,
portable toilet, wash basin
and washing stick, PNG

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BOX 1 Ann's Story

Completing high school was an achievement for Ann, and at the time she fell ill, she had been offered a place at college. Ann was healthy until giving birth to a son after an unplanned pregnancy. She became ill and was unable to look after her baby. Doctors carried out a test and confirmed that she had an AIDS related illness. She was approximately 20 years old, HIV positive and had 6-12 months to live. Ann's son was taken away. On leaving hospital Ann's family ostracised her and tried to stop the rest of the community from knowing that their oldest and well-educated daughter had AIDS. The community soon became aware of Ann having AIDS and also rejected her. Ann's family circumstances were typical of many rural families. Her parents had separated and she lived with her father and four brothers and sisters in a village more than two hours' drive from the nearest town. Ann's family lived in a bush material hut in front of a new house her father was trying to build. The floor area of the hut is approximately 18m². Inside, the house is divided by curtains into two small bedrooms, one of which was given over to Ann on her return from hospital.

of a workshop at the National Appropriate Technology Centre, one participant took a member of the project research team aside and said that she wanted to ask if the project could develop a spittoon from a small bucket or plastic container. She had been HIV positive for some time and one of her symptoms was a frequent need to spit out saliva. The day beforehand the workshop participants had been asked to list hygiene issues other household items they felt could be of help. After reviewing these lists we found no mention of the need for a spittoon. It was only after the 'touch, feel and smell' session with the Living with Dignity materials that her thoughts focussed onto other problems and a possible solution.

Personal Hygiene Kits

From these consultation workshops ATprojects selected four items to be included in its personal hygiene kits. The original

Ann's family collect water in an old 44 gallon drum, wash in a creek, have no electricity, use a dirt floor pit toilet and use fire wood for cooking. Traditional houses in Papua New Guinea are not equipped for the care of people living with HIV. Ann had no contact with the hospital or doctors after giving birth, was not taking any medication and suffered from acute and uncontrollable diarrhoea. She was so weak she was almost unable to walk the 25 metres to her family's pit toilet. When she did manage to reach the pit, she often fell backward while trying to squat and had to be helped up often with excrement and urine running down her legs.

The family purchased a metal bucket for Ann to use as a toilet, which was uncomfortable and painful to sit on. Ann used the bucket in the house at night and her excrement smelled very bad, so other family members began considering to move Ann out of the house into the old pig house. It is common in PNG for people with HIV to be "given" a no longer liveable house in which to live.

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Table 1 Solutions provided by the Living with Dignity program to WASH barriers

Barriers to WASH access faced by PLHIV	Solutions
Individual	
<ul style="list-style-type: none"> » Unable to walk to toilet » Diarrhoea » Rash » Weak » Poverty » Risk of opportunistic disease 	<ul style="list-style-type: none"> » Portable toilet » Portable basin » Portable/simple shower » Tools are light and easy to manoeuvre » Low cost » Allows PLHIV to be cleaner and lowers risk opportunistic disease
Environmental	
<ul style="list-style-type: none"> » Water supply or latrine is too far away/ not able to access water and sanitation when bedridden 	<ul style="list-style-type: none"> » Rainwater catchment system provided for private drinking water supply » Portable private shower system, hand basin and bucket toilet
Institutional/Organisational	
<ul style="list-style-type: none"> » Lack of access to medicines and doctors 	<ul style="list-style-type: none"> » Kit as first line of practical aid to dealing with disease and chronic illness symptoms » PLHIV are central to design and modification of hygiene kit
Social/Attitudinal	
<ul style="list-style-type: none"> » Misunderstanding of transmission and stigma means PLHIV face resistance when washing their bodies or clothes in rivers or common water holes; and » Stigma of their family members/ primary care givers 	<ul style="list-style-type: none"> » Providing PLHIV with a portable shower and washing stick and gloves » Education of community about transmission, alleviating stigma

personal hygiene kits included a bucket toilet, portable shower, washing stick and basin (Figure 2). Later, mattress covers and gloves were added. The selection process also considered the combined weight of the materials so that the kit can be easily transported by vehicle or carried back to a village.

The **bucket toilet** is designed with a plastic seat so that the user is able to sit comfortably on the toilet seat within the privacy of their house. Many HIV positive people are too weak to make the frequent trips to an outdoor toilet or field necessitated by constant diarrhoea. The bucket toilet can be easily placed next to the bed so that the person does not have to move far. The toilet's materials make it portable, lightweight and easy to clean. It also has a lid to control odour and flies.

People living with HIV often develop very itchy skin rashes and it is vital that they are able to wash daily to minimise the risk of infection from these rashes. The community response to PLHIV washing in the river is often negative, due to stigma and misunderstanding of transmission paths, and the person is often prevented from washing there. The **portable shower** can be placed within close proximity of the house, which means the user can wash daily without walking far or fear of discrimination. The shower includes an extended showerhead design so that care givers can wash the user without getting wet themselves (Figure 3). Black plastic sheeting is also included in the kit and can be used to construct a simple shower room.

The personal hygiene kit includes a **washing stick**, to assist with clothes washing done in a bucket. As with bathing, PLHIV face resistance from communities when using common water holes for washing their clothes. The washing stick allows the PLHIV or their care givers to wash clothes close to the house and reduces the handling of soiled clothes.

The personal hygiene kit also includes a **basin**. People living with HIV often suffer from fever, sweating and dehydration due to continuous diarrhoea. The basin allows the person to wash themselves while remaining

Figure 3
A participant demonstrates the portable shower and sheeting in PNG
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Figure 4
There are many challenges in distributing personal hygiene kits to remote and inaccessible communities in the PNG highlands

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Figure 5
Community members in the highlands receive distribution of personal hygiene kits

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Figure 6
The carers' kits include coffins made from plastic sheets

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in bed. Once the water is dirty they simply pull the plug, which drains the dirty water into a nearby bucket and refill the basin with clean water. When care givers return from their daily tasks they can then empty the bottom bucket of the basin and it is ready for reuse.

With the support of AusAID, ATprojects aim to produce 2,500 of these kits in 2012, an increase of 500 kits per year since the project commenced. The objective is to eventually produce 3,000-4,000 kits per year. Since the project commenced, a total of 12,500 kits have been distributed. Kits have also been sent to South Africa for a trial run in Durban. Each kit costs approximately US\$140.

The content of the kits changes based on user and distributor feedback. For example, the original gloves included in the kit were the medical style, which did not fit on

large hands and were not being used, so a successful change was made to introduce industrial style rubber gloves. The original showerhead was an expensive steel one. A more user friendly and cost effective plastic model has now replaced this. The original kit included a pulley for the shower system that recipients did not use; a simple rope has replaced this.

Some adaptations to the kit have not been possible due to cost restraints; a request for handles on the bucket toilet was not adopted for this reason. Instead written guidance and advice on building simple supports and frames is now offered. Another change to the kit has been to package the items in the kit so that it looks 'professional' and appeals to the local preference for quality products.

Table 1 provides a summary of some of the barriers to WASH access addressed by the Living with Dignity materials.

Distribution of personal hygiene kits

The aim of the distribution process is to provide a meaningful first response intervention to assist users. After diagnosis people affected by HIV often need to fend for themselves in rural PNG. Where the health sector is unable to provide medication, these kits represent the only practical assistance that many positive people will receive.

NAC staff in rural areas can distribute the kits (Figure 4 and 5). The staff receive training in the use of the kits and also in documenting the distribution process and collecting user feed-back. The lower the production cost, the greater the number of people that would be able to be reached. In terms of maintenance, the products needed to be almost maintenance free (apart from cleaning). This is not only because the products are sent to remote rural areas with little or no access to repair facilities, but also because rural users have few resources to repair broken equipment.

In 2012, ATprojects began trialling 250 carers kits which contain solar torches, headlamps, coffins (plastic sheets and ties) (Figure 6), aprons, gloves and mattress covers. These kits will be made available via Village Birth Attendant networks to increase the distribution range.

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Figure 7
The portable water catchment enables households to have their own nearby water supply
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Figure 8
The portable water catchment is made of durable but lightweight materials
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Water Catchments

ATprojects also address the environmental barrier of inadequate water availability for people living with HIV, which is common in rural PNG. It is estimated that only 32 per cent of the rural PNG population has access to an improved water supply. ATprojects believe this figure is much lower as many supplies installed during the past decades no longer work due to lack of maintenance and tribal conflicts.

The need

It is beyond the scope of this project to install a water supply in every village in PNG affected by HIV. The majority of people in rural areas usually fetch their water from small creeks or rivers, which can be many kilometres walk from their homes. The fetching of water is an important issue for healthy people, but for people living with HIV this water collection

can often be a matter of life or death. PLHIV are often denied access to traditional sources of water as it is wrongly assumed that they can pass on the disease through contaminating the water source. This situation makes it very difficult to realise even the most basic rights to water and sanitation, not to mention the added requirements of home-based care. Compounding this situation is the fact that any impurities in water can trigger opportunistic diseases and infections, which often hasten the death of PLHIV. There was a clear need to address this issue by developing a practical solution that could be introduced by non-technical NGOs, church and community volunteers who care for recipients.

AT projects' staff have seen a dramatic difference in overall health and wellbeing of people living with HIV who have had access to sufficient water for drinking, cooking and general washing of themselves and their clothes, compared to those who lack access. Monitoring of PLHIV's water use showed that approximately 12.5 litres of water is needed to meet the daily needs of a rural based person living with HIV. The research involved supplying 25 x 5 litre containers of water twice a week to a number of participants. The containers were then collected to see how much water was used, plus the participant's carer was asked to keep a simple record of how the water was used

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in terms of washing, cooking, drinking and laundry. The family of the person living with HIV must carry these extra 12.5 litres of water, and this responsibility is often passed on to either the mother or in many cases the elderly grandmother. This extra burden on top of a women's normal daily work and her role as the primary caregiver often results in high levels of stress within the family and in some cases, violence against or rejection of the person living with HIV.

Solution and distribution

One option developed by ATprojects is a small portable canvas water catchment (Figure 7). The portable catchment can hold 250 litres of water and does not need a corrugated iron roof. It is easy to carry and can be put up anywhere with ease. A problem faced in developing the design was finding the right type of fabric that would be strong enough to carry the weight of the water, which we wanted to store in the integrated tank. We chose PVC tarpaulin whose elasticity properties and ultra-violet resistance makes it an ideal material for our design. The next problem to be overcome was designing a shape for the tank that had no open seams that would leak. The tradesmen came up with a whole range of standard manufacturing techniques that we could use, with the aid of an eyelet punch and a PVC welding machine (Figure 8).

It was felt that providing the supports of the catchment would not only increase the cost of the unit but also make transportation much harder. The catchment was therefore designed to accommodate timber posts that could be obtained by the end user. While

the unit is only 1.5 meters high, this is high enough to ensure that it stays clean from surrounding ground pollution.

The cost of these units is currently US\$570. The current distribution model uses organisations at the frontline of providing care for people living with HIV to provide these units to individuals.

After

There is much stigma associated with people living with HIV, and to address the many practical day-to-day problems faced by these people, communities need to challenge their cultural and traditional beliefs. The solutions developed in this project do not address the attitudinal barriers of stigma and discrimination PLHIV encounter in PNG.

The Living with Dignity program is unique in its approach to addressing the barriers faced by recipients. The examples discussed here are all low cost and practical solutions. The personal hygiene kits are usually absorbed into the family of the PLHIV and can also be used to provide care for the elderly, heavily pregnant, injured or ill. The water catchment systems can be dismantled, returned and reissued by church organisations.

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This case study is one of sixteen from the Towards Inclusive WASH series, supported by AusAID's Innovations Fund. Please visit www.inclusivewash.org.au/case-studies to access the rest of the publication and supporting resources.

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