Building skills in disability inclusive WASH: Perspectives from a DPO in Timor-Leste

Disability

Joel Fernandes, Sophie Cooke and Huy Nguyen WaterAid



Background to Project

In January 2011, four agencies working in water, sanitation and hygiene (WASH)¹ and two working in disability² in Timor-Leste organised a seven-week visit from Huy Nguyen, an engineer and wheelchair user from Australia. The aim of the visit was to build an understanding of how the needs of people with a disability (PWD) could be incorporated into WASH programs in Timor-Leste, particularly in rural areas.

The visit was structured around a combination of workshops, technical design clinics and field visits, and involved participants from international and local organisations working in both the WASH and disability sectors in Timor-Leste. During this project, Huy worked closely with Joel Fernandes, a local member of the disabled people's organisation (DPO) *Ra'es Hadomi Timor Oan* (RHTO) and wheelchair user (Figure 1). The multiple stakeholders

Figure 1

Joel (left) and Huy
arriving in a community,
rural Timor-Leste

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BOX 1 Joel's Story

My name is Joel and this is my story of how I became disabled and how my life has changed since then. In 2006 I was in a car accident while travelling with my family, about 120 kilometres from Dili, the capital of Timor-Leste. At Dili hospital the doctor gave me the terrible news that I had a spinal cord injury and would never walk again. In desperation, I asked traditional healers to help me but no one could help me to walk again. This really made me sad to think I would never be independent again and maybe that I would never be able to go anywhere or do anything by myself.

One good thing happened to me while I was lying in bed in Dili hospital. Two people from an NGO in Dili called ASSERT came to visit me. ASSERT helps people with disabilities in Timor-Leste. First, they gave me a wheelchair and then they organised one week of training for me. There were ten of us in wheelchairs, and we learnt how people with spinal cord injuries can

still do many things for themselves. Before this training, I was just lying in bed and was totally dependent on other people for everything. But after the training, I could do a lot for myself, and ASSERT asked me to share my experience to help other people with similar injuries. This also led me to join the DPO.

Since I became involved with the DPO, I have become more aware of the challenges faced by people with disabilities. Many people do not understand disability and are afraid of it. We are treated differently because we can't do some things the same way as everyone else. My role volunteering at the DPO is to provide outreach to community members living with disabilities, giving them information and support. The DPO became involved with this project because Huy wanted to work with a Timorese counterpart. As part of the project, I travelled to Australia to share my experiences with the WASH sector there (Figure 1).

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¹ WaterAid in Timor-Leste (WATL), DWASH (USAID project implementing WASH programs), BESIK (AusAid project implementing WASH programs and working with the Government of Timor-Leste to draft policy, and build the capacity of departments working in water and sanitation) and Plan International

² The Leprosy Mission, and local DPO Ra'es Hadomi Timor Oan (RHTO)



Location

» Liquica District and Dili, Timor-Leste contributed financially to the project, and the aim of the project was for all agencies to adapt their learning to make their own WASH projects disability inclusive.

Context

There is a significant lack of understanding about the rights and needs of people living with disability in Timor-Leste, particularly in rural areas. Much of the country's population is rural and lives in poverty, and as such many PWD also face the challenges of poverty, often living in remote areas with poor accessibility and limited transport options. Some have quite severe physical disabilities, making access to WASH without assistance difficult. There is also a high level of stigma attached to being a person with a disability, and they are often excluded from community life with many choosing to remain in their homes. To compound this problem, there is still a general lack of basic understanding about the importance of sanitation and hygiene in some communities.

Participatory WASH projects that recognise and reconcile the rights of PWD are still in their infancy in Timor-Leste, and this is common to other sectors (e.g. education). The Government of Timor-Leste has neither signed nor ratified the UN Convention on the Rights of Persons with Disabilities (CRPD), although lobbying has occurred over the past few years to address this omission. At the time of this project, the National Disability Policy of Timor-Leste was being drafted and was submitted to the Council of Ministers for review in May, 2011. As of publication, it had not yet been passed.

The National Basic Sanitation Policy was also being drafted during the project and some of the organisations that participated in the workshop were also involved in the drafting of the policy, including BESIK as lead agency advising government on policy development. The policy has since been approved in January 2012 and integrates guidelines on inclusive requirements for rural water supply, water points and public toilets that were developed as part of this project.

Project Activities

The project closely linked field visits with practical problem solving sessions and training designed to build participants' capacity to address individual and environmental barriers to accessing WASH. The project involved the following steps:

- » Work with the most vocal advocacy body for rights of PWD (in this case The Leprosy Mission) to propose a disability-inclusive project to all WASH agencies in Timor-Leste
- » Gather data on challenges faced by PWD, with regards to accessing water and sanitation facilities and hygiene messages, and address some of the stigma and attitudinal barriers they face in their communities
- » Implement training for WASH agencies, the DPO and government
- » Develop prototypes for technical solutions such as assistive devices
- » Design water points to share with communities where PWD had identified barriers to accessing WASH
- » Develop a report on recommendations for stakeholders to continue with WASH projects
- » Follow-up on the commitment of stakeholders to disability-inclusive WASH in Timor-Leste.

Workshop participants visited rural communities to identify PWD within those communities, and talk to them about the challenges they face, particularly in accessing WASH facilities (Figure 2). After their trip, the workshop participants met to design prototypes which could be used

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Figure 2 Community member experiences what it is like to use a toilet while being blind, rural Timor-Leste

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Figure 3 Bamboo chairs with splash guard that could be placed over existing squat toilets, rural Timor-Leste

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Figure 4 Huy and Joel speak with school children about disabilities, rural Timor-Leste WaterAid in Timor-Leste



to show people how they could simply overcome issues related to accessibility. The participants then returned to the community to share their ideas with the PWD, their families and other community members. Prototypes were designed using local materials, so they would be easily replicable in communities. Examples included handrails made of bamboo in toilets, ropes to guide people with visual impairments to new facilities and bamboo chairs that could be placed over existing squat toilets (Figure 3).

As well as addressing physical limitations related to access, the project also attempted to address social and cultural barriers that prevent PWD from accessing WASH. One of the ways that this was done was by having two wheelchair users (Huy and Joel) visit communities to meet with other people with disabilities and their families, talk about their lives and access to WASH, and provide information to community members and local schools about disability (Figure 4). Huy and Joel found that people were happy for them to visit and embraced the opportunity to discuss their challenges openly with other people with physical disabilities who might understand their situation personally. They also mentioned how having Huy and Joel visit was a positive example about what they could achieve in their own lives. Some felt inspired to gain more independence for



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example through seeking employment or accessing assistive devices through the DPO such as a wheelchair.

In many communities people were surprised to see people in wheelchairs coming to their remote villages, and even more surprised when they realised that they were visiting in the capacity of trainers. Huy and Joel's visits helped to build more understanding about PWD and their rights through a series of activities and discussions. In one activity, community members without a disability were asked to understand the access challenges faced by wheelchair users and the visually impaired through role play (Figure 5). The trainers asked people to try and access the toilet or visit various places around the village while using a wheelchair or blindfolded. This activity allowed villagers to talk openly about the challenges faced by people with disabilities and older people. In these ways, the project began the process of overcoming some of the attitudinal barriers that PWD face living in rural Timor-Leste.

Figure 5
A man is blindfolded to experience what it is like to have a visual impairment, rural Timor-Leste

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Barrier and solution examples

After Huy and Joel's field visits, a one-week workshop was held for participants from agencies working in WASH and also in disability. The workshop built awareness about what disability is, and how to consider the needs of PWD, heavily pregnant women and older persons so they can better access toilets and water points. The workshop also included a field visit, so participants could see some of these solutions in practice. Together the workshop and the field visits provided examples of how disability inclusive WASH could be implemented in Timor-Leste, and provided a starting point for agencies to develop their own disability inclusive practices and policies.

Table 1 summarises some of the barriers identified, and possible solutions put forward by the workshop participants. These barriers were identified by PWD and their families through interviews during a series of field visits. Solutions were developed in the workshops through discussion and practical problem solving with the DPO and their members and WASH agencies.

The project was also innovative in its efforts to consider accessibility of the project at every level. Gender issues were considered through the inclusion of gender experts, who were actively involved in the project planning. The role of women as caregivers and helpers of PWD when using WASH facilities was also emphasised. Training materials and educational brochures were translated into local dialects, and workshops were held in the most accessible venues available, with adequate accessible transportation provided so that PWDs could attend the training.



 Table 1
 Barrier and solution examples

Barrier examples	Solution examples
Individual	
» Physical limitation (difficulty walking, squatting, balancing)	» Provide mobility equipment – wheelchairs, bamboo chairs, crutches,
» Poor eyesight	» Provide spectacles, white canes
» Lack of understanding about importance of practicing good hygiene	» Provide information booklets on health and hygiene to PWDs and their families
Environmental	
 » Long distance » Many steps to toilet and water points » Mud » Narrow toilet cubicles and doors, door opening wrong way » No support rails and seat » Slippery wet/dirty floor » Taps and pump handles too high » Tap difficult to use (e.g. turning instead of lever) » No privacy/open toilet 	 Install facilities closer to the user Construct low wide steps or make ramp with hand rails Put stones in the mud Cubicles with wider space inside, and wider doors opening outwards Provide support rails and toilet seat Improve floor surface and drainage Provide water point with taps at different heights and/or longer pump handles Provide alternate tap design
	» Build accessible and enclosed toilets
Institutional	
 » Lack of policies, strategies, legislation » Lack of information and skill of WASH staff » Lack of consultation with/representation of marginalised groups » Lack of standard design for accessible facilities » Lack of collaboration between relevant agencies 	 » Provide evidence and lobby to influence policy » Provide training to partner staff » Ensure elderly, PWD, women, etc. are represented on user committees » Involve representative groups of users, e.g. DPOs in designing/planning accessible facilities » Build partnership and capacity of relevant agencies
Social/Attitudinal	
 » Missing information about WASH needs of PWD, elderly people, pregnant women etc » Discrimination, neglect, exclusion » Negative thinking » Cultural beliefs » Hidden children with disability 	 » Improve information gathering using 2010 Census as a starting point » Advocacy for inclusion, make booklet » Raise awareness to change attitudes » Change attitudes, by teaching and reasoning around cultural beliefs » Raise awareness in families and the communities about inclusive education



BOX 2 Joel's story continued

After working on this project I was offered a job with the Leprosy Mission to be their focal person on disability inclusive WASH. Being involved in this training has provided me with a new career path. I visit people in their homes, look at their existing water and sanitation facilities and explain to them about how they can improve their access. I also provide training and information to other development organisations. I have learnt so much through this process, and I now have

the confidence and skills to help share my knowledge with other members of the community.

Timor-Leste's DPO is currently expanding to have greater coverage in the rural areas of Timor-Leste. In 2012 it is recruiting officers to be based in the districts, and we plan to train them all in WASH. In this way, I hope the DPO can play an important role as an advocate for PWD's right to WASH across my country.

Impacts and achieved changes of the project

Policy

Implementation of guidelines on inclusive accessibility standards for water points and public toilets was launched in February 2011 by the Government of Timor-Leste/BESIK and subsequently integrated into the guidelines for the National Basic Sanitation Policy. All new water points should now be built to meet the accessibility standards developed as a part of this project (see Supporting Resources).

Capacity Building

After participating in the workshop, DPO staff have an understanding of the concepts of inclusive WASH and can now help guide their members to find solutions to WASHrelated problems. For example, following the training the DPO was able to provide information to a school that had asked for advice on how to build a wheelchair accessible toilet for one of its students. Before attending the workshop, the DPO staff said they would not have been able to provide this type of support. By helping to deliver some of the workshop, the DPO also built its capacity as a disability inclusive development trainer. It is now well placed to provide similar workshops to stakeholders from other development sectors (see Box 2).

Promotion of Accessibility

Because of the frequent visits of wheelchair users during this project, the Dili offices at BESIK and the UN were made more accessible by the addition of ramps.

Learning points, challenges and lessons

Challenges

- » The bamboo chairs provided to some communities were not universally liked, as people thought they were not strong enough to support an adult. Participatory design of assistive devices can help to overcome resistance to new technologies.
- » Many PWD face stigma and discrimination because they are different from everyone else. Also, many are still embarrassed by their disability and do not want to leave their homes or villages. There is still a broad lack of understanding about PWD across all levels of society in Timor-Leste.
- » Low levels of education, especially in rural areas, means that local people have difficulty understanding the needs of PWD in terms of human rights.
- » Logistical problems, such as the challenging terrain of Timor-Leste and lack of adequate accessible transport and assistive devices, can hinder people with disabilities from travelling to the villages to be a part of workshops and community meetings.

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Lessons Learned

- » It is important to provide training to WASH field staff and give introductions about disability inclusive WASH, so that they will consider PWD's needs in their programs.
- » The success of WASH projects, which also address the needs of PWD, is strongly influenced by the involvement of the local DPO and local disability advocates at all stages of the project, including the early planning stages. In addition, involving PWD in development projects at early stages may help to preemptively resolve accessibility issues that may otherwise arise later in the project. Early involvement of PWD reduces the chance of expensive retrofits of water points and toilets further into the project.
- » A longer time period for the project (at least double the time) would have provided the opportunity to ensure that the rights-based approach to the WASH needs of PWD was better understood by participants. In addition, hindering factors related to logistics, language barriers and education levels could have been addressed.

One of the biggest remaining challenges is cultural. The western idea of independence is often at odds with cultural ideas of protection in a culture that is very family-oriented. In one village, the project team met with a visually impaired woman living on a cliff side. Her community and family

were protective of her and made sure that she was always safe. When we mentioned that she could probably attain more independence if they built guide hand rails leading to the toilet, they did not think it was a good idea because of concern that she might hurt herself if she travelled alone. This reluctance is even more pronounced in the case of younger children with disabilities. Their families are afraid they will not fit in with the other kids or get bullied so will resort to being over protective and frequently keep them at home. While it is important to be aware of the cultural context that trainers bring with them when on these projects, especially regarding issues of independence, protective family culture does not preclude the inclusion of people with disabilities in mainstream society nor projects designed to improve people's dignity.

References

» Nguyen, H (2011) Timor-Leste: Multistakeholder partnership in Inclusive Wash, Sanitation and Hygiene in Timor-Leste

Authors

Joel Fernandes

Leprosy Mission

Sophie Cooke

WaterAid

Huy Nguyen

Consultant

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.

