

Understanding disability and access to water, sanitation and hygiene East Sepik, Papua New Guinea



Introduction

Papua New Guinea's National Water, Sanitation and Hygiene (WASH) Policy 2015-2030 sets targets for provision of equitable, safe, convenient and sustainable water supply and sanitation by 2030. A core principle of the Policy is that WASH efforts *"take into account the specific requirements of disadvantaged and marginalized groups, including the very poor, women, infants and children, the elderly and people with disabilities"*.¹ Rolling out the Policy calls for specific attention on reaching and including women and men, girls and boys with disabilities, who may otherwise be excluded from WASH initiatives. Understanding what the barriers to WASH access are for people with disabilities, is a critical first step to sustainable and equitable implementation of PNG's national WASH policy.

Overview of disability in Papua New Guinea

People with disabilities in PNG experience discrimination and stigma with national advocates citing that the *"status of people with disabilities in PNG is extremely low and their voices unheard"*.² The Papua New Guinea National Policy on Disability (revised 2015) calls for: *"a barrier free physical and social environment for all"*. The National Disability Policy recognises that women with disabilities experience 'double disadvantage'. Official disaggregated data regarding prevalence of disability (including different impairment types) is not available in Papua New Guinea. The 2009–2010 Household Income and Expenditure Survey found 15% of respondents reported some level of difficulty with mobility and self-care and 3.4% reported a lot of difficulty or were unable to do them at all. The World Report on Disability estimates 15% of any population has a disability. Of the total population, at least 87 per cent of Papua New Guineans live in rural areas³ with little access to basic services such as hospitals and schools, much less safe water and safe sanitation. The first national level Disabled People's Organisation (DPO), the PNGADP (Papua New Guinea Assembly of Disabled Persons), was formed in 2002.

In Papua New Guinea, rural communities face challenges in accessing WASH, such as long distances to water sources and sanitation facilities, lack of proper sanitation facilities steep and rough terrain especially in rainy water, lack of available soap, lack of hygiene awareness and cultural norms around menstruation restricting access of women and girls to water, sanitation and hygiene facilities and practices during menstruation.

For people with disabilities, physical barriers (rough terrain, narrow entrances or steps) and stigma and discrimination make access to WASH facilities even more challenging, and can further limit their involvement in community planning processes. There are strong cultural beliefs about supernatural causes for disability in Papua New Guinea.

Understanding WASH and disability in East Sepik

In 2015, WaterAid undertook a scoping activity in East Sepik Province to better understand the WASH experiences of women and men, girls and boys with disabilities. The scoping activity was a collaboration between CBM Australia (CBMA) and WaterAid's local partners; Integrated Rural Development Initiative (IRDI), South Sea Evangelical Church (SSEC) and East Sepik Disabled People's Organisation (DPO). This paper shares key findings of interviews and focus group discussions with people with physical difficulties, and their carers across three communities.

An important note on language

The term '**disability**' is not familiar to most people in Papua New Guinea, where the scoping activity was conducted. In fact, there was not even a local term for disability. Therefore the scoping team used the term:

"physical difficulties", and explained it as:

"difficulties in performing physical functions such as walking, seeing, hearing, remembering or concentrating and self-care such as bathing".

This report introduces the term disability, but the findings section refers to physical difficulties.

¹ Ministry for National Planning & Monitoring (2015) Papua New Guinea National WASH Policy http://www.inapng.com/pdf_files/WaSH%20Policy%202015-2030.pdf

² National Disability Research and Advocacy Centre website, retrieved on 10 May 2015 from <http://ndrac.weebly.com/disability-in-png.html>

³ http://data.worldbank.org/country/papua-new-guinea#cp_surv

The aim of the scoping activity was to gain an understanding of the:

- **challenges experienced by people with physical difficulties when accessing water, sanitation and hygiene (WASH) and how it impacted on these individuals in the community.**

The scoping exercise aimed to gain a better understanding of:

- **whether people with physical difficulties experienced these challenges in a similar way to other community members; and**
- **how other factors such as gender, age and community attitudes also impact on the extent to which people with physical difficulties access WASH.**

Methodology and limitations

To address the scoping objectives, a qualitative information gathering process was carried out in three communities in East Sepik, where IRDI was delivering a WASH program. A three day preparatory workshop was co-facilitated by CBMA and the PNG Assembly of Disabled Persons and the East Sepik DPO representative.

Qualitative information gathering processes was conducted in June 2015 and included semi-structured interviews, focus group discussions, and a series of participatory activities including community mapping, timeline and pocket voting. Participants were identified via key informant techniques and drew largely on a baseline household survey which used the Washington City Group Questions (WCGQ's).⁴ A limitation of the scoping activity was that people with milder functional limitations participated. This was due to the WCGQ's being used incorrectly and picking up milder impairments. However this led to a positive unintended outcome: people with mild functional limitations were still very active in WASH labour, but that this caused great difficulty and potentially further impairment or disability. A specific focus was placed on exploring the diversity of experiences between people with different impairments, and the intersection of gender and age. The group included a number of older people, both those with significant functional limitations and those that were starting to experience age-related impairments.

Key findings of the scoping activity

1. People with physical difficulties experienced the same challenges in accessing WASH as others, but these challenges impacted them even more.

The scoping activities identified that whilst all community members experienced similar challenges in accessing WASH, the challenges proved more problematic for people with physical difficulties to overcome. For example, while all people in the community were challenged by steep and rough terrain and long distances to both water sources and toilets especially during rainy weather, people with physical difficulties found it even more challenging to navigate the difficult terrain over long distances.

“We face many challenges when collecting water for drinking and cooking, for example, when it rains the pathway to the water source is slippery, as there is wet gravel. Sometimes we slip and fall down with our water containers when returning back, and sometimes the containers break with the impact. When it rains it is difficult for us to collect water, there is also rubbish in the river.” (Woman with a physical difficulty)



WaterAid team member interviewing women with a physical difficulty about her WASH access

⁴The Washington Group Questions identify people with functional limitations, e.g. difficulty, walking, communicating, caring for self, hearing, seeing. This is considered internationally to be a reliable way of identifying people who are likely to be experiencing disability, given the complexity of the concept of disability and the

2. Women with physical difficulties experienced greater challenges in accessing water than men with physical difficulties and this had a greater impact on their lives.

In PNG women are largely responsible for water collection for household purposes; the maintenance and cleanliness of sanitation facilities; children's sanitation; and the hygiene practices of the family.



Young women with hearing impairment using sign language with her sister to describe her difficulties accessing WASH safely

"Only women collect the water, even when they are sick or have some physical difficulties. Even when we are very sick our husbands do not help us, other women assist us. The men and children are not allowed to collect the water; this has been our practice since the days of our ancestors." (Woman with a physical difficulty)

In comparison to men, the challenges in accessing WASH, especially water, had a greater impact on women with physical difficulties. This is because women were the main people in the household doing WASH-related work and were still expected to do this work even if they had a physical difficulty.

"Women with physical difficulties still have to go to the river to collect water, bathe and wash our clothes. Sometimes other people assist us, however most of the time we have to do everything ourselves." (Woman with a physical difficulty)

Men with physical difficulties also experienced challenges in accessing WASH; however their experiences were quite different to women with physical difficulties. This is due to the difference in men and women's socially constructed roles. Men are more commonly users of the water collected by others (women), or collectors of water only for their own personal use. Therefore their ability to

access WASH depended more on the availability of women to help them. Therefore the role of women as carers and WASH providers was an enabler for men with physical difficulties to access WASH. When men with physical difficulties did not have this assistance (e.g. if they were single parents or widowers), they experienced greater difficulties in accessing WASH.

"Men usually collect water for their own use. They have no consideration for the water needs of the household. The women will go to the river, bring water, come back and cook and then carry all the water containers and dirty dishes back to the river to wash." (Man with a physical difficulty)

3. Women with physical difficulties spent much longer time collecting water when compared to other women in the community.

This was due to the interaction of the following factors:

- Women with physical difficulties were not able to carry as much water as other women at any one time which meant they needed to make repeated trips to the water source.

'I have a physical difficulty and can only carry so



Older man unable to access WASH facilities and relies on daughter for all personal care

much water ... the amount of water I collect is not the same as the quantity that everyone else collects.'
(Middle- aged woman with a physical difficulty)

- b. Women with physical difficulties spent longer travelling to and from water sources than other women because they needed to travel more slowly to navigate the difficult terrain and distance.

"When I don't experience body aches then I can go back and forth quickly to the water source, but when I experience body aches then I walk very slowly to the water source and it takes me an hour to go and come back to the house." (Woman with a physical difficulty)

- c. Not being able to carry sufficient water and spending longer to collect water meant that women with physical difficulties had even less time for other work, including rest and relaxation

"We go down to the water source at least 3-5 times a day to collect water." (Woman with physical difficulty)

4. When accessing WASH, women with physical difficulties were more affected by gender based violence and cultural norms around menstruation when compared to other women in the community.

The scoping found that women in the community experienced high rates of gender-based violence. However, it found that women with physical difficulties may have been at greater risk of violence because of their WASH responsibilities. In a number of cases, the additional presence of physical difficulties served to exacerbate the existing dangers experienced by all women. For example, one woman who was hard of hearing reported she had been attacked and raped twice when going to fetch water, due to the lack of ability to hear oncoming intruders.

Cultural practices associated with menstruation further heightened the risk of violence, as menstruating women were expected to be discreet about toilet use and experienced behaviour restrictions. Women with physical difficulties described having to go to the toilet at night whilst menstruating so that men couldn't see them. Fears of being attacked while travelling alone, coupled with being unable to easily escape danger or protect themselves due to physical difficulties meant that some women ended up not going to the toilet at all.

Some of the violence experienced by women was precipitated by conflicts around WASH tasks, such as women with physical difficulties taking longer to fetch water. In some cases injury and physical difficulties resulted from gender-based violence, which then impacted upon the ability of women to work or carry out WASH responsibilities.

The cultural restrictions around menstruation also posed a safety risk for women who had additional responsibilities as carers for a child or an older family member with physical difficulties. Some female carers were the only member of the household able or socially permitted to collect water or cook. Therefore in order to provide for the family, some women described having to break the traditional taboos restricting their movements and water collection during menstruation. This was despite potential serious repercussions if it was discovered by the community that they had done so. Women with physical difficulties in this situation lived with the fear that breaking these cultural practices would increase the severity of their condition due to supernatural attacks by spirits angry over the breach in the taboos. This was a very real fear amongst the women; however they had limited choice but to continue with household duties which broke traditional



A group of older women with physical difficulties taking part in participatory activity of 'pocket voting'

taboos.

5. The age of a person with physical difficulties impacted how they experienced access to water, sanitation and hygiene.

The scoping identified that children, middle-aged people and older people had varied experiences of challenges in accessing WASH. This was largely due to household perceptions and responsibilities related to age and severity of physical difficulties of the individual. Feedback from the different age groups provided the following information:

Children with physical difficulties were supported to access WASH by their mothers and primary carers. This meant that the impact of difficulties in accessing WASH experienced by adults such as distance to water and toilets, difficult terrain and lack of hygiene awareness was significantly reduced. However being able to access WASH via their carers also meant that children were vulnerable to lack of clean water, adequate and safe sanitation and hygiene in their carers absence.

Adolescent girls and boys with mild or no physical difficulties had to provide for their individual WASH needs including supporting their mothers to collect water for the households over the long distances and sometimes difficult terrain. However, because of the gendered difference in the role



Family with two children with disabilities. Mother is on WASH committee which has helped progress disability inclusion in WASH program



An older woman shows rainwater harvesting system which she can access independently

of water collecting, adolescent girls with physical difficulties experienced greater challenges to accessing WASH compared to adolescent boys with physical difficulties.

Adolescent boys with physical difficulties were culturally expected to do less water collecting as female family members maintained the support that had been provided to them as children. In contrast, adolescent girls with physical difficulties were culturally expected to take on more responsibility for WASH related work, especially collecting water. This expectation was impressed upon adolescent girls even at a very young age, with families making adaptations to facilities around the home and processes to allow them to carry water with other women. If adolescent girls with physical difficulties remained dependant on mothers and family members to provide support for WASH tasks, they were then perceived poorly within the community. In some cases this led to social tensions within the community.

Older people with physical difficulties were well supported by immediate family members and to some extent extended family members to access WASH. This care was often provided by the female household members requiring women, and young girls to perform extra WASH related tasks to meet the needs of the older, such as collecting water, bathing the older at

home or to do their laundry. However the support that was provided to access WASH sometimes did not meet specific needs, for instance there was sometime provision of drinking water only, with insufficient water provided to support hygiene needs such as bathing and/or hand washing after toilet use or water for cooking. In many instances it was identified that those who were unable to access toilets practiced open defecation.

There was also a significant difference in the level of care provided to older men and women due to community attitudes towards gendered WASH roles. **Older women were supported once they were experiencing significant physical difficulties, such as near complete vision loss, or the inability to walk unassisted; whereas men were supported much earlier than women.** Older and middle-aged women, despite age related physical difficulties, were also still required to contribute to meeting WASH needs of the household they lived in, particularly water collection. This situation changed as they became quite old, and there were fewer expectations on them to collect water.

6. Community attitudes towards people with physical difficulties impacted on the extent to which people felt able to access community water, sanitation and hygiene facilities or receive assistance.

The scoping identified that people with physical difficulties often experienced reduced social status compared to other community members. This was particularly evident for women with physical difficulties. This impacted on the extent to which they were supported in accessing WASH and how community members treated them. Families of people with physical difficulties, particularly of deaf or hard of hearing women, reported that the community perceived some people with physical difficulties as “unimportant people”.

“We are finding it difficult doing our work with our physical difficulties; going out to gardens, fetching water. It is hard for us and when you are working, people will make a comment but they won’t assist.” (Woman with a physical disability)

In the instance that women with physical difficulties experienced gender based violence when collecting water, their lower social status meant that there were less repercussions for the perpetrators and where attacks were reported to others in sign language, this was not accepted as reliable testament by the wider community.

Women with physical difficulties from different geographic locations who had moved to the community because of marriage often had a particularly low status. The separation from immediate family members and relatives meant that this group had little or no support for WASH access from within their own household or community, as there was no obligation for a woman’s in-law family to provide support.

Five key learnings for water, sanitation and hygiene programs to consider:

1. Individual factors – age, gender and disability – intersect and directly impact a persons’ access to water, sanitation and hygiene, as with all areas of their life. It is important to recognise the diversity and power dynamics which exist in any community and to deliver programming in a way which does not reinforce inequalities and discrimination.
2. WASH programs must be designed to address needs that arise across the life cycle. Physical difficulties can be experienced by people from birth through childhood, adolescence, during adulthood and as an elderly person. The WASH



Example of a toilet adapted to be more accessible for younger family members

needs at each point of an individual's life cycle will vary, and people may require different levels of support to access WASH.

3. Directly addressing the challenges experienced by people with physical difficulties when accessing WASH also benefits other community or family members, such as carers, not just people with those difficulties.

4. Women with disabilities experience a unique set of challenging circumstances in accessing WASH which may be the same and different to other women. This needs to be specifically addressed by WASH programs to ensure they do not inadvertently increase inequality. A key question to always ask when addressing gender related issues in WASH is; *how does this issue affect women with physical difficulties?* In particular:

- Women with disabilities continue to do the same domestic duties as other women such as water collection, yet have more difficulty doing it and it takes longer.
- Risks of gender based violence are heightened for women with disabilities when accessing WASH who may not be able to hear or see attackers, nor escape quickly.

5. Community attitudes towards people with disabilities presents an additional challenge in access to WASH, as they may experience discrimination and are not always valued as contributing members of the community. A key question to ask when facilitating community engagement on WASH activity is; *are people with physical difficulties also included in the community conversations?*

WASH Programming recommendations for disability inclusion

1. Collect accurate data on women and men, girls and boys with disabilities within the community to support planning of WASH projects.
2. Proactively build relationships with local DPOs. They may be able to support processes to identify people with disabilities during planning phase of WASH projects. They can also make referrals for people with disabilities to access community-based rehabilitation and other disability support.
3. Ensure people with disabilities have a voice and are participating in all WASH processes along with other community members. This may require follow up consultation to find out what their WASH needs and preferences are.
4. When addressing women-specific WASH needs, ensure women with disabilities are represented in planning, information gathering and decision-making steps. Find out what their specific needs are and work with them to identify solutions, remembering that they are a particularly vulnerable and excluded group.
5. Ensure representation of persons with disabilities and/or carers on WASH committees, so their needs are raised in all decision-making processes.
6. Work with families to ensure that each family member can use their toilet and handwashing facility regardless of age, gender or disability. Consider adapting the design for ways to make it easier such as handrails, clearer pathways, easy to open doors, raised seats etc
7. Document learnings and approaches to disability inclusive WASH and share them with other WASH implementers in the sector.

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