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

A situation analysis across three communities in 2015

Full report
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INTRODUCTION

Papua New Guinea’s (PNG) National Water, Sanitation and Hygiene (WASH) Policy 2015-2030 has set ambitious targets for provision of equitable, safe, convenient and sustainable water supply and sanitation by 2030. PNG’s rural population face challenges in accessing water sanitation and hygiene. Women and children walk for long distances to water sources, in steep and rough terrain. Households often don’t have proper sanitation facilities, and there is often no soap and poor hygiene practices. Cultural norms around menstruation restrict access of women and girls to water and sanitation facilities and practices during menstruation.

The National WASH Policy contains 13 Fundamental Principles to be adhered to in its implementation. Principle 5 is that WASH activities, “take into account the specific requirements of disadvantaged and marginalized groups, including the very poor, women, infants and children, the elderly and people with disability”.

The inclusion of this principle is important given that we know from global practice that inequitable access to WASH is exacerbated by individual-related inequalities such as age, gender, disability and health. Focusing on the last part of Principle 5, the successful implementation of PNG’s WASH Policy will require participation from people with disabilities, who may otherwise be excluded from access to WASH. Clearly understanding the barriers to WASH access experienced by people with disabilities is a critical first step to sustainable and equitable implementation of the National WASH policy. To this end, WaterAid undertook a scoping activity in Papua New Guinea’s East Sepik Province to better understand the WASH experiences of women and men, girls and boys with disabilities.

Overview of disabilities in Papua New Guinea

People with disabilities in PNG experience discrimination and stigma with national advocates citing that the “status of people with disability in PNG is extremely low and their voices unheard”. 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 areas 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.

Poor access to WASH in rural PNG

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There are many barriers to accessing WASH in rural PNG, where basic drinking water coverage is estimated to be 30% and basic sanitation around 13\%⁹, some of the lowest coverage rates in globally. Therefore access challenges for people living in rural areas include:

- steep and rough terrain, especially in wet weather;
- long distances to both water sources and toilets, and/or lack of these facilities;
- 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, long distances to and from WASH facilities, narrow entrances, steep hills or steps) and stigma and discrimination make access to WASH services even more challenging.

**Intersection of individual factors**

People with disabilities are a diverse group, with diverse experiences. The impact of disability is impacted by a number of other factors, including the type and severity of the disability, gender, age and social status. Hence the impacts of disability on WASH must be considered alongside gender, age and social status.

This scoping report presents findings on how individual-related factors impacts on people’s WASH experiences, with a particular focus on gender and age.

**Scoping to understand disability and WASH: East Sepik**

A scoping activity was conducted to understand disability and WASH. The scoping activity was a collaboration between WaterAid, 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). The focus of the scoping activity was to better understanding of the experiences of people with disabilities in accessing WASH services in communities where WaterAid was supporting WASH services in the East Sepik province of Papua New Guinea (PNG).

The aim of the scoping activity was:

- to gain an understanding of the challenges experienced by people with disabilities when accessing WASH and how it impacted on these individuals in the community.

Specifically, the scoping exercise aimed to gain a better understanding of:

- whether people with disabilities experienced these challenges in a similar way to other community members; and
- how other factors such as gender, age and community attitudes, also impacted on the extent to which people with disabilities faced challenges accessing WASH.

This paper shares key findings of interviews and focus group discussions with people with disabilities, and their carers, across three communities.

**An important note on terminology**

The terms “disability” and "people with disabilities" are used in this report. Disability is a complex and evolving concept. It can be defined in a variety of ways, and reflects a continuum of experience.

It is important to note that local languages in PNG often do not have a direct translation for the term ‘disability’, and instead describe a person’s impairment type. Therefore, the scoping team used the term “physical difficulties”, explaining it to people as: “people who have difficulty walking, seeing, hearing, remembering or concentrating and self-care such as bathing”. For simplicity, the scoping process did not classify disability, nor ask people whether they viewed themselves as having a disability.

**METHODOLOGY**

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

The information was collected 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 identified people with disabilities through the Washington City Group Questions (WCGQ’s). A limitation of the scoping activity was that people with milder disabilities participated, due an incorrect use of the WCGQ's. However, this led to a positive unintended outcome: people with mild disabilities 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 disabilities and those that were starting to experience age-related impairments.

In terms of limitations, the findings of the analysis present greater detail of women’s than men’s experiences relating to WASH access. There was more participation by women than men. This could be due to women being more interested in discussing WASH or could be reflective of a higher prevalence of disability amongst women than men. In the communities visited, a number of the women had acquired their impairment (or an impairment had been made worse) through intimate-partner and gender based violence. This highlights the intersection between gender norms and disability, and access to WASH.

**OVERVIEW OF FINDINGS**

1. **The intersection of gender and disability: Barriers to WASH**

In the PNG cultural context, women are largely responsible for water collection for household purposes, the maintenance and cleanliness of sanitation facilities, children’s sanitation and the hygiene of the family. This is part of a rigid, gendered division of labour with clear boundaries as to which duties are performed by women and by men, but situated in a broader cultural value placed upon ‘hard-working’ women, which expresses itself in women being forced to perform the majority of household labour.

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‘It is the women’s responsibility to collect water. Men do not help; only young girls and women do it.’
(woman with disability)

‘Women bear the burden of collecting water and sometimes collect smaller quantities of water due to the fact that they have difficulty in collecting large amounts of water.’
(middle-aged woman with disability)

‘It is true that we here in the community, plenty people have the attitude that we hardly help the women to carry water’
(male participant)

The scoping study found that gender exacerbated the degree to which a person’s disability impacted on their ability to carry out their culturally prescribed WASH duties, and therefore the impact of the barriers to WASH on their daily life. While women with disabilities had varied experiences of access to WASH, in general the impact for them was greater compared to men.

This difference is due to the men’s WASH roles being more commonly as users of the water collected by others (women), or collectors of water only for their own personal use. Men, therefore, are free of the burdens that women suffer, both in terms of the amount of labour expected of them, and the nature of that labour, in terms of women having other people dependent on them, and being under the social expectation that women should serve others, as indicated by the quotes below.

‘As for me, I am a lazy man who only does gardening work. I feel tired when I come and if there is not water in the house, it is usually my wife who goes to the river to collect water. She collects the water containers as well as packs up the dirty dishes to take down to river to wash. This is extra on top as she usually carries the water containers on her head. When she is sick, I am a lazy man, a lazy father, as I do not help her in the house. This is what we men usually do.’
(male participant)

Wife: ‘When a man collects water, it is just for him to drink, wash his own hands and mouth. When he goes to the river, it is only because he wants it for himself to bathe.’

Husband: ‘That is right… every day we never have sufficient water to meet all our needs in the house. For us men, we go to the river, just to bathe and come back. We will not collect any water for the house, we will just carry a little water container for our own use.’
(conversation between wife and her husband with a disability)

‘Some men 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 disability)

Situation of women with disabilities in accessing WASH

As discussed above, WASH roles in PNG are clearly differentiated by gender, with women burdened with an increased amount of labour, and an expectation to labour in service of others.

The study identified that women with disabilities, particularly if these were mild or moderate, were not exempted from these gendered inequities, and were often still expected to do WASH-related work for the household.

‘Even though we have physical difficulties we have to access water, unless it is raining and then we use rain water.’
(older woman with disability)

Many of the women with disabilities had physical impairments (which affected walking or lifting abilities) and difficulty seeing. This meant that the barriers of distance and terrain experienced by all women in fulfilling their socially-prescribed role as water-collectors, were exacerbated for them. They often described having to spend much longer than other women travelling to water sources and toilets, and much longer doing WASH-related tasks such as water collecting and carrying, washing clothes, dishes etc. They were typically able to carry smaller amounts of water than other women, and had to make repeated trips over the long distances to the water source.

‘I have a physical difficulty so I can only carry so much water … so it’s not the same as the quantity that everyone else collects.’
(middle-aged woman with disability)
‘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 disability)

‘The water source is too far for me and I can’t go more than once a day.’ (woman with disability)

‘It is hard for me to collect a lot of water, I can only collect water in 2 litre water containers.’ (woman with disability)

Reaching a toilet, using a squat toilet without assistance were common barriers for people with disability in the community. This was due to the squat toilet design, as well as the distance to toilets, which were often uphill and over difficult terrain. Although the geographic challenges are common to all people in the communities, as the quotes below illustrate their impacts are felt more by women with disabilities.

‘The toilets are located far away at night so we have to walk some distance to the toilet.’ (woman with disability)

‘I have knee problem, when I do a lot of work my knee swells up…. When I come back home after being in the garden it is swollen when I have to go to the toilet I have to stand and do my business, I cannot sit on the toilet/squat.’ (older woman with disability)

Women with disabilities sometimes reported accidentally defecating and urinating on themselves when travelling the long distance to the toilets, or accidently soiling the toilets when they were unable to squat. These incidents had a direct, physical impact by requiring them to collect additional water to clean the toilets and bathe themselves, but also a social and emotional impact, undermining dignity and potentially leading to judgements from others.

‘Even people with disabilities still have to go use the same toilet far away and sometimes accidentally pee or defecate on themselves on the way to the toilet and then they go and wash themselves afterwards. We need toilets to be located nearby to make it easier for us.’ (woman with disability)

There were also issues related to toilet hygiene, tied both to limited availability of soap, and water use not being prioritised for handwashing given the difficulties associated with collecting water.

‘Water taken from the river is for cooking and washing of cooking utensils only and not for bathing or hand washing’ (elderly woman with disability)

‘In the morning, I would go to the toilet come wash my hands and sit down and I don’t eat with spoon I eat only using my hands … that is why I would wash my hands with water my wife would fill up the big saucepan…If there is soap I can use soap to wash my hands, if not then I just use water’ (elderly man with disability)

‘There is nothing to wash hands after toileting except when there is extra water available we use’ (elderly man with disability)

‘If we have money to buy soap then we use soap if not nothing’ (daughter of elderly man with vision impairment)

The issue was further compounded by the fact that for women with disabilities, who were overburdened with multiple responsibilities, including providing for WASH needs of the household and care of other individuals, were often unable to meet their own WASH needs as exemplified by the quote below.

‘When I am busy working and need to defecate I do so straight away but don’t bother with hand washing. Yet when I am not busy then I take the time to wash my hands after using the toilet.’ (woman with disability)

Whilst women with disabilities on the whole reported exacerbated barriers to WASH due to the gendered division of labour, a small number of women shared positive examples of men assisting with WASH-related work in the family. One such instance, the assistance was attributed to the husband being on the WASH committee and better understanding the division of labour. This was described as a significant enabler, which could potentially be strengthened through WASH programs.

‘My husband sometimes assists with collecting water and firewood, however he is not supposed to do this all the time. Collecting water is a woman’s job’ (wife of man on WASH committee)
‘There are many of us men here, who worry about our women. We do not want to give burden to the women.’ (man with disability)

Being heavily engaged in household WASH work, women with disabilities said they did not have time for rest and recreation. It also impacted on their health and wellbeing, potentially causing or exacerbating existing disabilities. Some of the women had experienced physical difficulties, including back pain, swelling, loose joints, severe migraine, fatigue and weakness in limbs, from collecting and carrying heavy loads on their heads over long distances, including carrying large quantities of water uphill from the water source. However, due to social pressure women with disabilities felt they had little or no opportunity to decrease their workload or avoid their socially prescribed role of collecting water.

I usually have to carry heavy loads of sago bags and firewood bundles which has affected my back and now I have a bad back’ (woman with disability)

I usually assist my husband with some of his tasks; in fact, I do all the work. Whenever I feel that my knees are aching I have to rest for one full day and then I will feel better. (middle-aged woman with disability)

Women with disabilities also experienced a sense of despondency at the constant difficulties of everyday life, including family tensions in their household as family members expressed frustration over what was perceived as slowness in performing household tasks or reduced work output.

‘For myself, I feel like my body is not good, I feel it is difficult to carry heavy things. I feel sad and sometimes I cry...and I used to feel pity for myself when I stay.... I find it very hard to carry water or work in the garden so my children help me, then I am able to carry the water.’ (older woman with disability)

‘My sister gets annoyed with me every time she has to collect water for me and she says things like... don’t use too much water as you will waste what I have collected, just use what is sufficient for your needs’ (woman with disability)

Gender-based Violence: Links to WASH

Women in PNG experience high rates of gender-based violence13, and the interaction of disabilities and WASH responsibilities can mean that women are at greater risk of violence. The need to travel long distances to access WASH can make women with disabilities particularly vulnerable to violence while fetching water or going to the toilet. Gender-based violence in the family can also be precipitated by conflicts around WASH tasks for women with or without disabilities, and can be exacerbated for women with disabilities, for example when they take more time than others to fetch water.

In some cases, injury and disabilities resulted from gender-based violence, which then impacted upon the ability of women to work or carry out WASH responsibilities.

‘When I walk to the water I feel pain in my legs and in my head a very bad headache. I was sick for three months and was bedridden when it started, I can’t concentrate well, I can’t think well ... I start things and forget and do other things and I can’t see well either. Also, my husband hit me and broke my arm, the bone shattered into pieces and I should have had some pins put into it but I didn’t go to the hospital and so I can’t lift this arm and my fingers don’t move and are not flexible so I can’t carry anything on this side, so my children help me and have to carry things for me.’ (middle-aged woman with disability acquired as a result of GBV)

‘I am a widow, my back is quite painful when I carry heavy loads, and my left hand is weak. My husband’s younger brother hit me and he broke my wrist and the bone has not set well so it’s hard for me to carry things or do heavy loads, it’s very weak so I don’t carry heavy loads. The same man stabbed me with a knife on the right side at another time and so I find it very difficult to work and my hand gets very weak and tired.

on that side so it’s both sides. I have pain in my knees so it’s hard to carry water.’ (woman with disabilities acquired as a result of GBV)

In a number of cases, having a disability exacerbated the safety risks experienced by all women.

‘I go by myself to collect the water, it’s not safe and I have difficulty collecting and bringing the water in the container.’ (woman with disability)

‘There are also men who follow the women on the way to the river...’ (woman with disability)

‘We still have to go and collect water because there is only one source and we need it, but we feel very scared because we can’t run fast and some of us can’t see well.’ (woman with disability)

‘When women go to collect water and go through the bush they are scared that men will be hiding in there and they will come and attack them. This happened to one young girl’s sister who has impairment, they came out and tried to rape her, we knew who this man was yet we did not report this case’ (woman with disability)

The researchers were told of two cases of women with hearing difficulties who had been attacked, and in one instance raped, when going to fetch water, due to a lack of ability to hear oncoming intruders.

The lower social status given to some people with disabilities compounded this danger further. Families of people with disabilities, particularly of deaf or hard of hearing women, reported that the community perceived them as "unimportant people". Where attacks were reported to family members using sign language, this was not accepted as reliable testament by the wider community.

**Menstruation: Impact on women as carers**

The restrictive cultural practices associated with menstruation create difficulties for all women in PNG. During the scoping activity, women with disabilities talked about menstrual hygiene practices. However it was difficult to ascertain if their practices were different to women not experiencing disability. For example, when menstruating, all women depend on other women to collect and bring water to them for drinking and bathing, as well as having food cooked by other women and brought to them.

‘When we have menstruation we live downstairs, and the toilet is further away during the night we can come down and go or if we feel toilet than we can wake our friend to accompany us to the toilet. If there is no one to help me go to the toilet at night I just try to forget about it and go to sleep till the next morning when I can go to the toilet.’ (woman with disability)

Therefore, we cannot disentangle the barriers to good menstrual hygiene experienced by women with disabilities compared to those without disabilities. Similarly women said that lack of money was a reason for not having sanitary pads. However the scoping activity was not able to identify if this was different for women without disabilities.

‘We just walk without any wrappers ... we just remain without anything while it flows as we don’t have enough money to by wrappers every time’ (woman with disability)

The cultural restriction around menstruation posed a safety risk for women who had additional responsibilities as carers for a child or an elderly family member with disabilities. Some women carers were the only family member responsible for collecting water or cooking. They described having to break behavioural restrictions and continue their role of collecting water while menstruating. Women said they were fearful of repercussions if others knew they were doing this. Some said they also feared that this might lead to an increase in the severity of their disability by spirits.

‘There is no other way. Sometimes when she goes to bathe [while menstruating], she would carry water for me. Otherwise, no one will get water ... Yes, it is hard with the custom. But for me, who is going to help me? That is the reason why she just carries water.’ (husband with hearing impairment discussing why his wife collects water during her menstruation period for him and for their son with intellectual disability)
Social status: a barrier to WASH access

Social status was another key variable that influenced the impact of a disability on an individual’s access to WASH. Factors including gender, traditional wealth, leadership, education and kinship ties help to dictate an individual’s status within the community. Men typically having more status than women.

Participants, particularly women with disabilities, described negative attitudes towards them because they were considered to be poor, weak or helpless. They felt this impacted how the community provided assistance in meeting their WASH needs. Women with disabilities felt that the community expected them to demonstrate their worth through hard work, including collecting water for household or community needs.

‘People just observe and sit amongst themselves but they won’t help you. They will say you aren’t walking properly, you are walking in a crooked way, but they won’t help.’ (elderly woman with disability)

‘We are finding it difficult doing our work with our impairments, going out to gardens, fetching water. It is hard for us and when you are in the work place they will make a comment but they won’t assist.’ (woman with disability)

Women with disabilities described having a reduced status compared to other community members, with their limitations interacting with other factors to impact on WASH access. For example, women from different geographic locations who had moved to the community because of marriage often had low social status, which when combined with disabilities meant they experienced particular difficulties in accessing WASH. 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-laws to provide support. This lower social status in the household and lack of support for WASH needs in the community due to lack of kinship ties, thus increased the impact of their disabilities, as indicated in the quote below from a woman who had moved from her village after marriage.

‘I always feel physically sick and unwell. I find it difficult to carry a big load. I feel sad and sometimes cry. I do not feel supported living in this village and I find it difficult to work in the garden and collect water. My children do not assist me so I go home to my own village and receive support and care from my immediate family- my parents, my brothers and sisters and when I feel well I return back to this village. I find it difficult living here because of the pain and weakness in both my hands’ (elderly woman with disability)

Situation for men with disabilities in accessing WASH

Men with disabilities reported a variety of challenges in accessing WASH, however their experience varied according to their age, social status and severity of disabilities. In general, they were not required to contribute to WASH work within their households or community, so their ability to access WASH depended more on the availability of women to help them. Generally, the role of women as carers and WASH providers was an enabler for men with disabilities to access WASH. For instance, some men with disabilities had wives who assisted them to access WASH services; however, others were single parents or widowers, and thus experienced greater difficulties in accessing WASH.

Men more often reported difficulties linked to issues accessing sanitation facilities and hygiene related concerns, including having little or no water and soap for hand washing and bathing, and having to practice open defecation when unable to travel to toilets located too far away.

‘For myself, when I am sick or my wife is sick, there is no one to care for us. I have to manage as best as possible and collect water for us. I help my wife to fetch water, and if she is sick then I have to collect water myself and vice versa for her. We have to collect water every day before we go and do other work like gardening. However, when my wife is very sick then it is hard for me to get water, it is mountainous’ (man with disability)
When he wakes up in the morning, he defecates anywhere he likes. I tried to take him to the toilet, however he refuses to go with me so he would just defecate wherever he likes and I would remove it and carry it to the toilet (daughter of elderly man with vision impairment)

‘I am 50. I have a problem with my right leg sometimes I cannot walk, it’s swollen and painful and I creep. My family looks after me to fetch water ... I cannot carry heavy loads, if I do I develop pain again.’ (Man with disability)

‘If someone is getting water for you it is only for cooking and drinking, not for bathing. The water fetched by others is only used for cooking. Men are not allowed to get water for women. (Man with disability)

2. The intersection of age and disability: Barriers to WASH

The analysis identified that the age of a person with a disability impacted on how they experienced access to WASH. For instance, children, middle-aged people and elderly people had varied experiences of barriers and enablers for WASH. This was largely due to household perceptions and responsibilities related to age, and severity of disabilities of the individual.

Children with disabilities

During the scoping activity, children were reported to be well supported to access WASH facilities, especially by their mothers and primary carers (in some instances fathers). This meant that issues such as distance to water and toilets, difficult terrain, and lack of hygiene awareness and materials were largely mitigated by carers.

The ways that carers reduced the barriers to WASH for children with disabilities included collecting water for children, and building them separate toilets that were easier to use and closer to the house. Some children without disabilities were also built separate toilets.

Both boys and girls with mild or no disabilities often assisted their mothers in collecting water for the households, over long distances and sometimes difficult terrain. This was difficult for children with disabilities, however not doing this meant they might miss out on social opportunities with their families and peers.

Families of children with intellectual difficulties reported additional learning barriers to hygiene and sanitation practices, which in some cases meant that their children practiced open defecation.

‘When he wakes up in the morning he toilets anywhere he likes: I try to take him to the toilet he does not like it so he would just drop it wherever he likes and I would remove it and carry it to the toilet ... the children and I have dug a small pit toilet but he refuses to use the toilet.’ (mother of child with intellectual/learning difficulty)

It was clear that for women who are carers of children with such impairments that the socially-prescribed WASH role is exacerbated and difficult to fulfil:

‘Because I care for a child with a disability, my purpose is to carry water for drinking and cooking but if I get plenty than I can use it for other purposes ... when I bring water up and he does not go to the toilet properly and if he rubs faeces on his body then I will wash him with this water I brought. That is it, all water is gone. In the morning, whatever remaining water and if he toilets and soils himself then I have to wash him and go back a second time on this day to get water.’ (mother of child with intellectual/learning difficulties)

‘Caring for my child stops me from doing my normal work, so sometimes we don’t have enough food or water for the family in the house.’ (mother of child with disability)

Due to concerns for children’s health and well-being, parents often provided soap and small quantities of water near the house for children to wash their hands after toileting. Thus, with the exception of children with intellectual
difficulties, it appeared that children with disabilities could largely access WASH via their carers but this dependence meant they were vulnerable to lack of water, sanitation and hygiene in their carer’s absence.

Adolescents with disabilities

The social norms of the community dictate different roles for boys and girls when reaching adolescence. In PNG, the change from childhood to adolescence signifies maturity and greater independence for children, especially from care by and contact with their mothers. It is at this time that girls are expected to take responsibility for WASH-related work for the household. Hence the support provided for accessing WASH generally decreases, and the family expects adolescent girls to contribute to household duties as well as provide self-care for WASH needs.

This means that adolescent girls with disabilities experience more barriers to WASH as they are expected to rely less on carers and provide more WASH support to the family, despite their disabilities. There was evidence of preparation for this transition in some families with some mothers preparing younger girls with disabilities to find ways to carry water. In contrast, adolescent boys, with or without disabilities, could theoretically expect to do less WASH-related work than girls their age, as female family members maintained the support provided to them as children. However other factors also impacted upon a person’s involvement in WASH-related work: for example, one adolescent boy with a disability still helped his mother with WASH work, apparently due to his limited social connections and closeness with his mother.

If adolescents with disabilities, particularly girls, remain dependent on mothers and family members to provide this support, they are then perceived poorly within the community, which can lead to social tensions and potential repercussions from family members due to strict social norms which dictate that women should participate in heavy physical work. The scoping activity did not identify whether this was the same for adolescent boys who are dependent on carers. For example, whether male-gendered norms of avoiding spending much time with women, mother or family and with peer groups instead

Elderly people with disabilities

The standard cultural practice in PNG is to provide care and support to elderly men and women in their old age. This is due to the belief that the elderly have lived out their lives as custodians of land and traditional heritage and contributed much towards sustaining their family lineage and community, hence the need for the family and community to acknowledge and reciprocate in some way. Usually this is provided by immediate family members (usually women, although occasionally men) who provide physical care and support for the elderly person including bringing them water, and assisting with toileting and bathing.

‘I live with him and for toilet he goes himself to the toilet. He goes toilet finish and then he comes back. Truly for bathing, I would bathe him. For bathing, sometimes when he badly needs washing that is when I would bathe him.’ (male carer of elderly man with disability)

‘My grandchildren are here, they will hold my hands and will slowly and gradually go down to the river. My grandchildren will get the water for me to which I will use to wash my hands and eat. To use the toilet, they will hold my hand and we will go down to the bush ... the children collect water for me to wash in the house.’
(elderly woman with vision impairment)

This meant that the impact of some barriers, especially distance to water and difficult terrain, was largely mitigated by carers; however other barriers such as access to toilet, soap and water for bathing and hand washing were still challenges for some elderly people. Many were not able to walk over long distances unassisted, especially due to loss of eyesight, hearing and/or weakness in their limbs. Some had trouble accessing toilets located far away and would accidently defecate or urinate whilst on the way to toilets, thus requiring additional water and soap to clean themselves. For others who were unable to go to the toilet, open defecation was practised near their homes. Some participants described great shame associated with this.
‘If I go and sit and toilet and people see that I would feel ashamed ... it is not a good thing that people should look at me and I defecate, defecating is when we hide.’ (elderly man with vision impairment)

‘People with vision impairment usually go to the area near the house to defecate than our children will clean up after us.’ (elderly man with disability)

‘My children and grandchildren get water for me. Sometimes when they get water I use that water to wash myself but if they do not get enough water for 2-3 days I go without washing.’ (elderly man with disability)

‘When I go I would be ashamed to wash when there are lots of people around. I will only wash if I am alone.’ (elderly woman with vision impairment)

The challenges experienced by the elderly in accessing WASH were further exacerbated by their experiences of isolation, loss of social status, disrespect and break down of social norms for community care and support especially towards the elderly.

‘When I didn’t have this vision problem I use to go to out to the community to listen to the meetings and all these, and now my vision is affected I do not go out.’ (elderly man with vision impairment)

The WASH needs of the elderly were provided by immediate family members, and to some extent extended family members. This support was often provided by the female household members, requiring women and adolescent girls to perform extra activities to meet the WASH needs of the elderly, such as collecting extra water to bathe the elderly at home or to do their laundry.

‘My father is quite old and it is a huge task in looking after him. I have to give him a bathe, cook for him and collect water for him over a long distance as the water source is too far away. There are ten of us in the family, however I am the only one who takes care of him.’ (daughter of elderly man with vision impairment)

‘Because the water source is downhill it’s really hard to get to it and I have to get my children to go to the water source. Sometimes they get angry and complain. When I ask my daughter to get water, she feels sorry for me as her father so she does most of the water fetching. The son doesn’t do much.’ (elderly man with a disability)

In many instances, it was the grandchildren who assisted their mothers to meet the WASH needs for the elderly, specifically related to water for drinking, bathing and toileting. However, there was little priority given to providing soap for hand washing and bathing, which was a common finding throughout the scoping activity, not just specific to elderly people. The level of care and support provided to the elderly differed between households depending on how family members perceived the age of the individual and the impact of their disability on accessing WASH services, as well as perceptions of the ‘value’ and abilities of an individual based on their gender.

There was a marked difference in the WASH support provided to elderly men and women. Women were supported once they were experiencing significant disabilities, such as near complete vision loss, or the inability to walk unassisted; whereas men were supported much earlier than women. Gender differences meant that elderly and middle-aged women, despite age-related disabilities, and the related impacts on their ability to perform physical labour, were still required to contribute to meeting WASH needs of the household they lived in, usually in the role of water collection.

‘My grandchildren are here, they will hold my hands and will slowly and gradually go down [to the water source with me]. I would bathe, refill water for drinking and then come up.’ (elderly woman with vision impairment)

The quotes below point to the impacts on older women who were unable to fulfil these expected roles of household water collection.

‘In the past, I was physically fit and it was easy for me, but due to difficulty in my body I cannot do a lot of activities and now sometimes go without food because of the difficulties and nobody is willing to help me e.g. I cannot wash my own clothes’ (elderly woman with disability)

‘In the past, I could see well, however lately my eyes are not good, and I cannot see well. I cannot leave my house and go out, I just stay at home ... no water, I just stay at home, if rain falls fills the drums then I can fill it up and bathe.’ (elderly woman with vision impairment)
However, this situation changed as they became quite old, and there was less expectation of them to collect water.

Support for water access also sometimes did not cover all of a person’s basic water needs, and there was evidence that carers had to prioritise water uses.

‘I am the carer of an older woman: [when I collect water] it is only for cooking, I don’t collect water for her to wash or drink.’ (middle-aged woman with disability)

**DISCUSSION**

What are the key learnings?

It is clear that individual factors – age, gender and disability – intersect and directly impact a persons’ access to WASH, 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.

Women with disabilities experience a unique set of challenging circumstances in accessing WASH, given the intersection of disability with gendered inequalities present in the division of WASH-related labour.

To ensure we do not increase inequality, when engaging with women and girls with disabilities, WASH programs must address both their status as people with disabilities, while also dismantling unjust gender roles and relations.

The key question to always ask when addressing gender-related issues in WASH is, “**how does this issue affect women with disabilities?**”

This recognises in particular that:

- 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, and:

- risks of gender based violence are heightened for women with disabilities when accessing WASH who may not be able to hear or see attackers, or escape quickly.

With respect to the intersection of age and disability, WASH programs must be designed to address needs that arise across the life cycle. Disability can be experienced by people from birth through childhood, adolescence, during adulthood and as an elderly person. The WASH needs at each point of an individual’s life cycle will vary, and people may require different levels of support to access WASH at different stages of their life.

Improving people with disabilities access to WASH is something that benefits the entire community, and should motivate action. A community-wide view can be taken, recognising the benefits to other community or family members, such as carers, not just people with those difficulties.

From the scoping activity, it is clear that community attitudes towards people with disabilities presents an additional challenge in their access to WASH. People with disabilities experience discrimination and are not always valued as contributing members of the community.

In order to overcome this, a key question to ask when facilitating community engagement on WASH activity is, “**Are people with a disability also included in the community conversations?**”
Recommendations for more inclusive WASH programming

- Collect accurate data on women and men, girls and boys with disabilities within the community to inform planning of WASH projects and bring visibility to their needs.

- Proactively build relationships with local Disabled People’s Organisations. They may be able to support processes to identify people with disabilities during planning phase of WASH projects. DPO’s can also make referrals for people with disabilities to access community-based rehabilitation and other disability support.

- 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.

- 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.

- Ensure representation of persons with disabilities and/or carers on WASH committees, so their needs and rights are raised in all decision-making processes.

- 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, and raised seats.

- Document learnings and approaches to disability inclusive WASH and share them with other WASH implementers in the sector.

CONCLUSION

It is evident in Papua New Guinea that rural communities face a range of barriers when accessing WASH services: rough terrain, long distances to water source and toilets (including lack of these facilities), lack of available soap and hygiene awareness and cultural norms and practices. This scoping activity endeavoured to explore how this situation impacted women and men with disabilities.

The quotes and stories from women and men and carers highlights how disability interacts with other factors: age, gender and social status; to affect a person’s WASH experience. It is a reminder that an individual’s experiences of barriers and enablers in enjoying their rights to water sanitation and hygiene need to be well-understood to design inclusive, accessible and empowering WASH solutions.

It provides rich information and voice for WASH policy-makers and programming implementers in rural PNG, to be more aware of inequalities, harmful power structures and a critical need to support people to overcome additional barriers, as a means to ensure that no one is left behind.