Water, Women and Disability Study: Key Findings

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A multi partnership collaboration

- Lead partner: World Vision
- Funded by the Department of Foreign Affairs and Trade’s Women for Water stream
- Baseline data collection within the Laetem Dak Kona project
- Partners: LSHTM, Vanuatu Society for People with Disability, Vanuatu Disability Promotion and Advocacy Association, Vanuatu National Statistics Office, Ministry of Justice and Community Services, Sally Baker (independent consultant)
Outline

- Study Methodology
  - Household Listing
  - Nested Case-Control Study
  - Qualitative Component
  - Key Study definitions

- Disability Prevalence
- Water and Hygiene
- Sanitation
- Lack of information drives taboos
- Surviving versus Thriving
Study Methodology
Study Methodology

Mixed methods research design: the WHAT and the WHY

1. A mini-census of all households in TORBA and SANMA provinces (n=55,000) using Washington Group Short Set

2. A nested quantitative case-control study of 800 people with disabilities and 800 people without disabilities

3. An in-depth qualitative study of menstrual hygiene and incontinence management with:
   • 54 individuals
   • 13 key informants
Menstrual Hygiene Management (MHM)

- A clean menstrual management material
- A private and accessible place to change the menstrual product
- Water and soap to wash the body and materials used
- Proper disposal of used materials in a safe and dignified way
- Accurate information on the menstrual cycle and how to manage it with dignity
- Addressing harmful social beliefs and taboos

Menstrual hygiene poster. Credit: BRAC
Incontinence

• Incontinence is a complex health and social issue, which involves the involuntary loss of urine or faeces or both

• Severity of incontinence varies significantly from occasional to regular leakages and a constant threat of urinary infections and bladder complications

• In this study, we included people who experienced incontinence 2 to 3 times a week
What is disability inclusive WASH?

- Waterpoints, latrines, bathing shelters and handwashing stations that are:
  - Easy and safe to reach and use
  - Built in an accessible way so that everyone can use them comfortably

- Challenging misconceptions and negative attitudes related to disability

- Ensuring information and processes are accessible to people with different impairments

- Policies and guidelines take disability into account (costing, national standards on accessible public WASH designs)

- Promoting free and meaningful participation of people with disabilities in research, policy and programme design

“Nothing about us without us”
Disability Prevalence
Disability Prevalence

Lower than estimates using WGSS in other regions e.g. 3.8% Nepal, 5.9% Cameroon, 7.4% Guatemala, 7.5% India

Comparable to Samoa Monograph (2.7%) – Same Methodology

<table>
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<th>Province</th>
<th>Male</th>
<th>Female</th>
<th>5 - 17</th>
<th>18 - 35</th>
<th>36 - 49</th>
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<td>2.1</td>
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<tr>
<td></td>
<td>Total</td>
<td>Rural</td>
<td>Urban</td>
<td></td>
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%
Water and Hygiene
Access to Water

- 91% of households overall have access to an improved water supply, although this is lower in rural households (89%) compared to urban (99%)

- Water availability is insufficient for over half of all households (57%) with no difference between rural and urban

- Majority of households the water source is not on premises but less than 30 minutes round trip

- Men and women with disabilities less likely to collect water themselves than men and women without disabilities

- Amongst those who do: less likely to feel safe when collecting water

![Water Source Location Graph](image)
Menstrual taboos

• All participants believed that menstruating women and girls will kill crops
• That menstruating women and girls must not:
  • Work in the gardens
  • Cook food
  • Lift heavy objects (or else the menstrual blood will flow more heavily)

• Many believed that they must:
  • Collect their own water for bathing and washing their reusable Menstrual product
  • Wash their own menstrual product
  • Use separate latrines and bathing shelters
Menstrual taboos add layers of difficulties for people with disabilities

“The water source is far. I want water closer to me so I can get it easily.”

© Liti Akimere
Menstrual taboos add layers of difficulties for people with disabilities

“I would like a better bathroom where I can sit properly.”

“Washing for myself is hard.”

© Liti Akimere
Bathing

- One woman (43 years) has incontinence and is unable to sit out of bed

- Four year-old son cares for her: collects water, cleans her bucket latrine, prepares food. Does not attend pre-school

- She tries to manage incontinence and menstruation independently by having bed baths and only having a full shower once a month

“And then he said, “Mama, I’m too tired now.” And then he’ll sleep without eating. I’ll feel sorry for him. “Don’t fetch water, just wet the towel at its end and bring it here. “When he comes, I think about that I have to at least wash my private parts. I clean my private parts – I use the towel to wipe from my bum to the front. But I don’t wipe my full body because he’s tired.”

(Woman, 42 years, disability – walking, self-care, incontinence and MHM)
Sanitation
Household Sanitation

- 55% of households have access to an improved sanitation facility overall (47% in rural and 81% in urban).
- 47% urban and 33% rural HH shared facility with one or more households.

Amongst people with disabilities:

- 86% use the same facility as other members of their household.
- 38% need assistance to use the toilet (more likely: mobility, memory or self care limitations, older people and women compared with men).
- 32% find it difficult to use the toilet without coming into contact with faeces or urine (more likely: mobility and self care).
The majority of people with disabilities use the same toilet as other household members, but this not accessible.

“Accessing the toilet is impossible, unless I have someone to assist me.”

© Fred Sewen

“I want a better way to be able to use the toilet.”

© Liti Akimere
One participant became disabled after slipping and falling on the way to her toilet
Inaccessible latrines: the impacts

“Eating, bathing and toileting in one room is unhygienic”

©Edline Elton
“When her stomach is really sore, she has worms come out... sometimes they come out of her mouth, and sometimes out of her bum.”

(Carer of woman, 58 years, disability – hearing, walking remembering and concentrating, incontinence, rural)
People with disabilities are more likely to experience incontinence.

- **Urinary IC**
  - Experiences Incontinence (binary): 13% with no disability, 32% with disability
  - A large amount: 20% with no disability, 13% with disability
  - A moderate amount: 40% with no disability, 20% with disability
  - A small amount: 40% with no disability, 5% with disability
  - None: 20% with no disability, 15% with disability

- **Fecal IC**
  - Experiences Incontinence (binary): 16% with no disability, 30% with disability
  - None: 20% with no disability, 15% with disability
  - A small amount: 40% with no disability, 30% with disability
  - A moderate amount: 40% with no disability, 30% with disability
  - A large amount: 20% with no disability, 30% with disability

- **Leak Frequency**
  - Once a day or more: 5% with no disability, 5% with disability
  - Two to three times a week: 10% with no disability, 5% with disability
  - Once a week or less: 30% with no disability, 30% with disability
  - Never: 30% with no disability, 30% with disability

- **Leak Amount**
  - No disability: 0%, 0%
  - Disability: 20%, 30%
Lack of information drives stigma and taboos
Incontinence

• No word for incontinence in Bislama or local dialects

• Healthcare workers reported not receiving training on incontinence

• Many participants with incontinence had been diagnosed with diabetes, but were not told that incontinence is a symptom, or how to manage it

• Reasons why people don’t talk about it: shame, fear of what others would say or think, belief that it’s a normal part of ageing, never been asked

“I’m scared [...] I’m scared to talk about it [...] I’m also ashamed to mention it. When we went to the hospital and waiting to be attended to, urinary incontinence occurs almost always.”

(Proxy interview, man, 18 years, disability – walking, remembering/concentrating, self, care, understanding/communicating, incontinence, rural)
Menstrual hygiene management

• Very few accounts of formal education in school about puberty and menstruation

• As menstruation is linked to sex (a taboo topic), menstruation is not spoken about openly

• All participants had limited understanding of the biology of menstruation

• Information provided focused on practical management: use a menstrual product to soak up menstrual blood. Not:
  • how often to change the product
  • how to dispose of it in an environmentally friendly and hygienic way

• Frontline healthcare workers reported not having any training on menstrual hygiene management or disability
Surviving versus Thriving
Participation and satisfaction

Subjective Wellbeing (Cantril Self-Anchorong Striving Scale)

- Women with disabilities: 18% Struggling, 65% Surviving, 5% Thriving
- Men with disabilities: 17% Struggling, 56% Surviving, 23% Thriving
- Women without disabilities: 4% Struggling, 56% Surviving, 40% Thriving
- Men without disabilities: 5% Struggling, 54% Surviving, 41% Thriving
Survive and thrive?

Ageing, disability and incontinence discrimination inhibits a person’s ability to survive and thrive

“I’m all alone [...] I’ll just be here... if I’m hungry I’ll go look for them [family], but they don’t care for me.”

(Woman, 74-year-old, disability, incontinence, rural)

“I don’t like to go out because if I need to go to the toilet and my clothes get wet... in front of other people, I will be ashamed. So I just stay here.”

(Woman, 59 years, no disability, urban)

“Because people here don’t care about people like this. They just see them as a piece of dirt or something [...] So we can’t take them outside.”

(Proxy interview, woman, 58 years, disability, rural)
“When you can do everything for yourself, you feel that you are free and you feel that you have peace and joy in your heart.”

(Woman, 61 years, urban, walking functional limitation)
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Thank you for listening