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## Research paper

# “I’m scared to talk about it”: exploring experiences of incontinence for people with and without disabilities in Vanuatu, using mixed methods

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## ABSTRACT

**Background:** Incontinence is the involuntary loss of urine and/or faeces. It is stigmatised and can reduce quality of life. People with incontinence require water, sanitation, hygiene (WASH) and incontinence products. People with disabilities are at risk of experiencing incontinence and may face challenges managing, however, minimal evidence exists.

**Methods:** This study aimed to complete a population-based study of disability in TORBA and SANMA Provinces, Vanuatu to quantify the prevalence and demographics of disability, experience of WASH access and incontinence for people with and without disabilities. We completed a survey, case-control study, in-depth interviews, structured observations and PhotoVoice. 179 people with disabilities and 148 people without disabilities completed the incontinence module in the case-control study. We applied purposeful sampling to select 27 people with and without a disability from the nested case-control, and 16 key informants for the qualitative study to further explore the impact of incontinence on people's lives.

**Findings:** People with disabilities were three times more likely to experience incontinence than people without disabilities (Adjusted Odds Ratio 3.3, 95% confidence interval 1.8 – 5.8). Challenges facing all people with incontinence were distance to latrines and lack of incontinence products. People with disabilities were less able to wash and participate in social activities. Less than 10% had assistive technologies; caregivers had no lifting devices. People experiencing incontinence did not disclose this to others, including medical professionals, who also did not raise the issue.

**Interpretation:** Inaccessible and inadequate WASH, lack of incontinence products and stigma increased isolation for all people with incontinence. Additionally, people with disabilities and caregivers faced discrimination and insufficient assistive technologies. This negatively affected their wellbeing and quality of life, and requires addressing.

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## Research in context

**Evidence before this study** Incontinence is the involuntary loss of urine and, or faeces. It can negatively affect a person's quality of life, as well as their caregiver's. People at risk of having incontinence include people with disabilities, espe-

cially those with underlying health conditions, older people, pregnant and new mothers, and children. People who experience incontinence may require an incontinence product, nutritional advice and healthcare services. They also need information about how to manage it and continuous access to water, sanitation and hygiene (WASH). Existing evidence on incontinence is predominantly from clinical or care facility settings in high-income countries, where healthcare systems are developed and water, sanitation and hygiene services exist.

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In low-and middle-income countries (LMICs), it is likely that people with and without disabilities who experience incontinence face challenges managing it, but minimal data exists.

**Added value of this study** This is the first mixed-methods study in a LMIC to explore how common incontinence is among people with and without disabilities, the role of WASH facilities in management and its effects on wellbeing. It covers two provinces in Vanuatu, SANMA and TORBA, the latter being the country's most geographically remote.

Using mixed-methods allowed us to present broad trends, reasons for these and how they impact on people's lives. It enabled an assessment between how people with and without disabilities experience incontinence differently. We also define 'inclusive WASH', which is a term that is widely used but not specified.

This is a collaborative study across disability, WASH actors and academics in Vanuatu and the UK: the London School of Hygiene & Tropical Medicine (LSHTM), World Vision Vanuatu, Vanuatu National Statistics Office (VNSO), Vanuatu Society for People with Disability and Vanuatu Disability Promotion and Advocacy Association.

**Implications of all the available evidence:** This study shows that incontinence is widespread in Vanuatu, and that more people with a disability experience it than those without. Findings demonstrate the importance of inclusive WASH, accessible devices and improving access to affordable incontinence products. Coordinated action must be taken to destigmatise incontinence and increase support to those who experience it, and their caregivers in Vanuatu and other LMICs.

## 1. Introduction

A person experiences incontinence if they are unable to control when they urinate or defecate (or both). Severity varies from managing sporadic to regular leakages, which cause skin sores, smell, urinary infections and bladder complications [2]. It is a debilitating condition which is often associated with stigma and negatively impacts on quality of life.

Incontinence affects a wide range of people including children, expectant and new mothers, older adults, and people with disabilities. In 2003, a meta-analysis of population-based studies from 35 countries, mainly from high income settings, revealed that 27.6% of females experience urinary incontinence globally, and this increases with age [3]. Risks related to ageing are also relevant for people with disabilities. Disability is defined in [Box 1](#).

### Box 1.

The International Classification of Functioning, Disability and Health (ICF) defines disability as an umbrella term for impairments, activity and participation limitations [1]. A person with a disability experiences an impairment (e.g. intellectual), which is caused by a health condition (e.g. cerebral palsy) that interacts with contextual factors that are individual (e.g. sex, age) and societal (e.g. access to WASH) to influence the person's functioning and participation.

An estimated one billion people have a disability globally [4]. Among these, approximately, 110-190 million adults have substantial difficulties in functioning and may rely on professional or informal caregivers [4]. Not all people with disabilities experience incontinence, but they are at a greater risk because of underlying health conditions, such as spinal cord injury, immune system disorders, and injuries or diseases of the nervous system [5-7]. They may also experience incontinence because they are unable to reach

a facility in time when they need one because there is no accessible facility, or the path to it is unsafe, or they are unable to communicate their need to those around them [8]. There is a marked lack of data from low-and middle-income countries (LMICs), and with poorer access to health services, including maternity services, and higher rates of disability and health conditions linked with incontinence (such as diabetes), the prevalence in these settings may be higher than the global estimate [9-13].

People who experience incontinence have many healthcare, service and information needs as a result. They require medical attention, nutritional advice, information on incontinence management, access to incontinence products (such as pads, bed pans, commodes, latrines); clean water close to home for drinking, bathing and washing clothes and bedding; soap to wash the body and laundry, as well as a safe and private place to bathe [14-16]. However, coordinated efforts across the health, water, sanitation and hygiene (WASH) and disability sectors to respond to the issue are absent in LMICs, and incontinence is shrouded in stigma and taboo [15].

Access to safely managed WASH services are pivotal to health, well-being and economic development [17, 18]. Since 2000, progress has been made to improve access to WASH globally, but stark inequalities remain. National, regional and global estimates between 2000 – 2017 released by the Joint Monitoring Programme (JMP) for WASH, show that nearly 75% of the population in Least Developed Countries (LDCs) still do not have access to handwashing facilities with soap and water [19].

Eight in ten people lacking basic water services globally live in rural areas and almost half live in LDCs [19]. Disaggregated data highlights that the richest wealth quintile's access to basic water and sanitation tends to be 50% higher than the poorest quintile (data from 24 and 48 countries respectively) [19]. Globally 80% of people with disabilities live in (LMICs) [4]. Furthermore, this group is generally over-represented in the poorest wealth quintile and often have less adequate access to WASH services than people without disabilities [20]. We previously reported the additional barriers people with disabilities often face in accessing WASH [21]. People with disabilities may also require assistive devices (e.g. wheelchairs, walking canes) and support structures (such as handrails, raised toilet seats, commodes, bedpans) to enable independent access to latrines and bathing shelters, and manage any incontinence. However, the WHO estimates that only 5-15% of people who need assistive devices receive them in LMICs [22]. Additionally, knowledge about ways to adapt household WASH facilities to make them more accessible in these settings is low ([23, 24]). Consequently, people with disabilities, who are at risk of experiencing incontinence, may not have access to the WASH services that support management strategies, and face double discrimination.

The JMP estimates that in Vanuatu, an archipelago comprised of approximately 83 islands in the South Pacific Ocean, only 44% of people have access to safely managed drinking water; 34% to basic sanitation and 25% to a basic handwashing facility in the home (using UNICEF/WHO Joint Monitoring Programme definitions) [25]. Comparatively, the JMP estimates in the nearby Solomon Islands that 68% of the population have access to safely managed drinking water, 34% to basic sanitation and 36% to a basic handwashing facility at home [25].

Vanuatu has pledged to progressively realising the rights of persons with disabilities and the rights to water and sanitation for all its citizens: it has ratified the United Nations Convention on the Rights of Persons with Disabilities (UNCPRD), developed policies, strategies and action plans, as well as set up a Disability Desk in the Ministry of Justice and Community Services [26]. The National Sustainable Development Plan 2016 – 2030 includes Objective 2.2 "Ensure all people have reliable access to safe drinking wa-

ter and sanitation infrastructure” [27]. The Government of Vanuatu also collects data on disability and published analyses of these, and Vanuatu National Statistics Office will release prevalence data this year [26]. However, there is a dearth of rigorous evidence about access to WASH services for people with and without disabilities who experience incontinence.

The Water, Women and Disability study (2019) aimed to rectify this by completing a comprehensive population-based study of disability in TORBA and SANMA Provinces, to measure disability prevalence and understand access to, and experiences of WASH, menstrual health and incontinence for women and men with and without disabilities. The study was a baseline assessment to inform the design of the Laetem Dak Kona (LDK) project: an inclusive WASH programme targeting people with disabilities and women in the TORBA and SANMA Provinces. [Box 2](#) defines ‘inclusive WASH’.

### Box 2. Defining Inclusive WASH

There is no agreed definition of inclusive WASH. We define it as a process which addresses the barriers to accessing and using water, sanitation and hygiene (WASH) services faced by people who are vulnerable to exclusion, including people with disabilities, older adults, people living with chronic illness, women, girls, transgender and non-binary people.

For people with disabilities, inclusive WASH means effectively participating in and informing WASH-related research, policy and programme design and implementation. All people with disabilities, regardless of their impairment and where appropriate, including their caregivers, can access and understand information provided, which is also made relevant for their specific WASH requirements. Information dispels harmful misconceptions that perpetuate disability discrimination. All people with disabilities can reach water points, latrines and bathing shelters safely. Public and private WASH facilities, including disposal mechanisms for menstrual and incontinence materials, are safe and accessible for everyone to use with dignity. Caregivers are supported to provide WASH-related care that promotes the self-respect, dignity and autonomy of the person with a disability.

WASH related policies and guiding documents include activities and indicators that support the progressive realisation of the right to water and sanitation for people with disabilities. Service providers understand policy commitments and are supported to realise them. Progress and exclusion are monitored and reported on, with persons with disabilities central to the process.

Details of how the study used mixed methods to generate evidence for inclusive WASH policy and programming in Vanuatu, and study results related to disability prevalence and its associations with access to WASH at a household and intra-household level are published elsewhere [21]. This article presents novel in-depth qualitative and quantitative findings on how common incontinence is among people with and without disabilities, the role of WASH facilities and the effects on individuals’ participation and wellbeing. [21]. Further results related to menstrual health and socioeconomic predictors of WASH access are forthcoming.

## 2. Methods

The study methodology is described in detail elsewhere [21]. In brief, we used a mixed methods approach entailing both qualitative and quantitative components to complete a comprehensive population-based study of disability in TORBA and SANMA Provinces, Vanuatu, to quantify the prevalence and demographics of disability, and understand access to and experience of WASH,

and incontinence for women and men with and without disabilities.

The quantitative component (Feb – July 2019) comprised 1) a population-based survey and 2) a nested case-control study. The qualitative component, (May – July 2019) comprised in-depth interviews, structured observations, a market survey of incontinence materials and PhotoVoice.

### 2.1. Study setting

TORBA and SANMA are the two northernmost provinces of Vanuatu. They consist of small to medium islands, which can be reached by boat and small planes. SANMA is sub divided into twelve area councils, and one municipality, Luganville, which is the only urban setting across the two provinces. SANMA has the greatest burden of WASH-related diseases per 1,000 persons in the country [28]. Access to clean water and improved sanitation facilities is lower than national averages (30% and 21% respectively) [29]. TORBA has six area councils and is the most geographically remote province in the country, with the highest number of islands.

### 2.2. Population-based survey

A complete listing of all households across the two provinces was undertaken (an expected 68,000 individuals in 14,000 households) [30]. Each household that agreed to participate first completed a household roster, before all household members aged 5+ were screened for reported functional limitations using the Washington Group Short Set and Mental Health Questions. Following standard Washington Group criteria, participants were considered to have a disability if they answered “a lot of difficulty” or “cannot do” to any of the domains of the Short Set [31]. The results from this study component are reported elsewhere [21].

### 2.3. Case-Control Study

We recruited a sub-sample of people with disabilities identified in the household listing (“cases”), alongside an equal number of age (+/- five years), sex and location-matched “controls” into the nested case-control study. Based on the expected prevalence of disability, and expected differences in sanitation outcomes between people with and without disabilities, a sample size of 800 people with disabilities and 800 without, stratified by age group, was required. Questionnaires were drafted building upon prior research activities and using standardised modules where available. No standardised survey modules on incontinence were identified in the literature, so we developed a module in collaboration with subject experts that was forward and back translated by the study team. However, during quantitative data collection, it became clear that low familiarity with the concept of incontinence among both data collectors and community members had led to misinterpretation of these questions. The module was revised, and field teams underwent further training and mentoring to better understand incontinence before proceeding. Consequently, data on incontinence are reported only for the sub-sample of the Case Control study enrolled after this point.

Participants with incontinence reported the degree to which incontinence interfered with their lives on a scale of 0 to 10 using the Cantril Self-anchoring ladder, which was reported numerically as their incontinence interference score [32].

Development of data collection tools drew on existing quantitative case control questionnaires developed by the International Centre for Evidence on Disability (ICED) and were reviewed to ensure consistency with the National Sustainable Development Plan

**Table 1**  
Study population characteristics

Study population	Female/male		Age range			Location		Functional domain				
	Female	Male	18-30	31-64	65+	Urban	Rural	Hearing	Mobility	Cognition	Self-care	Communication
Disability (n=9)	3	6	2	4	3	7	2	0	7	1	3	0
Proxy: details of disability (n=10)	6	4	4	6	0	3	7	2	8	5	6	5
No disability (n=8)	6	2	0	5	3	4	4	N/A	N/A	N/A	N/A	N/A

(Vanuatu's People Plan) 2016 – 2030, the Vanuatu National Disability Inclusion Development Policy 2018 – 2025 and the Laetem Dak Kona Monitoring and Evaluation Framework [27,33].

#### 2.4. Qualitative Study

Details the study population characteristics are presented in Table 1. Women and men with and without disabilities were included if they experienced faecal and / or urinary incontinence at least three times a week. To understand the wider context, we interviewed two healthcare service provider professionals in urban and rural areas, five national level government officials involved in WASH and health policy, two implementers focusing on WASH, and seven professionals working for Organisations of Persons with Disabilities or disability service providers.

We applied purposeful sampling to select 27 participants from the nested case-control study. All potential participants were asked: 1) their age, 2) the Washington Group Short Set of questions to confirm their disability category [31], and 3) if they experience urinary and / or faecal incontinence at least three times a week. Individuals who did not meet the inclusion criteria were excluded. Caregivers (proxies) were interviewed if any participant did not fully understand the consent process, and answered our questions on behalf of the person with a disability. In order to compare people's experiences, we intentionally sampled women and men with a variety of functional limitations, ages and rural or urban location, and then matched them with people without a disability. We were unable to achieve representation across every variable, so we applied snowball sampling, whereby participants and research team members identified additional participants.

Qualitative data generation tools developed drew on inclusive participatory methods that the London School of Hygiene & Tropical Medicine (LSHTM) research team have designed and piloted for exploring sensitive topics with people with disabilities [34]. We also collaborated with leading academics and practitioners working on incontinence in LMICs, World Vision, Vanuatu Society for People with Disabilities and Vanuatu Disability Promotion and Advocacy to ensure our questions explored incontinence sensitively and in a culturally relevant way.

##### 2.4.1. Data analyses

We applied methods triangulation across in-depth interviews, observation, Focus Group Discussions, Key Informant Interviews, and PhotoVoice and ranking to support consistency of findings. Data was analysed iteratively: at the end of each day the research team met to discuss emerging findings and interview technique, and review field notes and sample size. When data collection was complete, voice recordings of the interviews were translated and transcribed into English. The accuracy of the transcriptions was checked by the Ni-Vanuatu research team and any discrepancies were corrected.

Data was analysed thematically. Initially the research team had a one-day workshop to discuss the findings and group them into themes, such as *Management strategies* and *Water availability*. Transcriptions were loaded into Nvivo 11, and data were coded into themes identified by the research team, with sub themes generated for greater detail. For instance, *Limits water and food* sub

theme was added under the *Management strategies* theme; *Bathing* and *Drinking* sub theme were included under *Water availability* theme. Codes were compared and relationships between them were identified and analysed. Finally, a report was produced capturing the findings.

Quantitative Case-Control data was analysed in STATA 14.0 using descriptive statistics and multivariate logistic regression to generate odds ratios comparing outcomes for people with and without disabilities, adjusted for confounders (age, sex, location and socio-economic status [SES]). SES scores were generated via Principal Component Analysis (see elsewhere for details) [21]. We used a binary cut off of experiencing either urinary or faecal incontinence at least once a week, and at least a small amount to categorise people as having incontinence. We applied this cut off to both people with and without disabilities enrolled in the case control study to determine our sample for these analyses.

#### 2.5. Ethical approval and informed consent

Ethical approval was given by the LSHTM's Observational Ethics Committee (Ref 16202/2019) and endorsement was provided in writing from the Ministry of Justice and Community Services, in the absence of an Ethics Committee in Vanuatu.

Written informed consent was sought before every qualitative and quantitative interview. The PhotoVoice consent was comprehensive: written consent was sought at the start of the exercise, and again once the photos were taken. This ensured participants fully appreciated the purpose of the activity, what was captured in the images, how images would be used and if they would like their real name or a pseudonym credited. Pseudonyms are used for 'George' and 'Selina'. However, Fred Sewen requested that his full name is used and that his original images appear in the manuscript.

Pseudonyms are used throughout the article along with broad age ranges when quotes are used. Details of impairments experienced have been excluded.

After data collection, World Vision Vanuatu, Vanuatu Society for People with Disabilities and / or the Vanuatu Disability Promotion and Advocacy staff who collaborated on the research, followed up with participants to ensure that they did not experience psychological or social harm as a result of their involvement in the study. Additionally, the LDK project is actively working to develop approaches to enable people to better manage incontinence and challenge the stigma associated with the condition.

#### 2.6. Role of funding source

This study is funded by the Australian Government's Water for Women Fund and donations from the Australian public. The funder had no role in the study design, data collection, analyses, interpretation or in documentation.

**Table 2**  
Disability and Incontinence (at least once a week and at least a small amount)

	People with disabilities (n=179)		People without disabilities (n=148)		Age, Sex, Location, SES adjusted Odds Ratio (95% CI)
	N	%	N	%	
Urine or faecal incontinence	80	45%	31	21%	3.4 (2.0 – 5.8) <sup>†</sup>
Urine Incontinence	61	34%	22	15%	3.3 (1.8 – 5.8) <sup>†</sup>
Faecal Incontinence	54	30%	24	16%	2.3 (1.3 – 4.0) <sup>†</sup>
<b>Interference Score</b>	Mean Score (Standard Deviation)		Mean Score (Standard Deviation)		p value <sup>§</sup>
Urine incontinence	4.7 (3.1)		5.0 (2.5)		0.6
Faecal incontinence	5.1 (2.8)		4.5 (2.7)		0.2

<sup>†</sup> p<0.001 or <sup>†</sup> p<0.05 multivariate logistic regression

<sup>§</sup> t-test

**Table 3**  
Factors associated with experiencing incontinence among people with and without disabilities

People with disabilities (n=179)				People without disabilities (n=148)											
Urine (n=61)				Faecal (n=54)				Urine (n=22)				Faecal (n=24)			
n	%	Age, Location, SES	adj Odds Ratio (95% CI)	n	%	Age, Location, SES	adj Odds Ratio (95% CI)	n	%	Age, Location, SES	adj Odds Ratio (95% CI)	n	%	Age, Location, SES	adj Odds Ratio (95% CI)
<b>Age Group (years)</b>															
5 – 17	13	36%	Baseline	10	28%	Baseline	5	14%	Baseline	6	17%	Baseline	6	17%	Baseline
18 – 49	24	33%	1.1 (0.4 – 3.0)	18	25%	1.5 (0.5 – 4.3)	10	14%	0.5 (0.1 – 2.0)	12	17%	0.7 (0.2 – 2.1)	12	17%	0.7 (0.2 – 2.1)
50+	24	34%	1.2 (0.4 – 3.3)	26	37%	2.1 (0.7 – 6.4)	7	17%	0.9 (0.2 – 3.7)	6	14%	0.7 (0.2 – 2.6)	6	14%	0.7 (0.2 – 2.6)
<b>Sex</b>															
Male	20	23%	Baseline	24	27%	Baseline	9	14%	Baseline	9	14%	Baseline	9	14%	Baseline
Female	41	45%	3.1 (1.5 – 6.6) <sup>†</sup>	30	33%	1.4 (0.7 – 2.9)	13	16%	1.5 (0.5 – 4.2)	15	18%	1.5 (0.6 – 4.0)	15	18%	1.5 (0.6 – 4.0)
<b>Location</b>															
Rural	26	26%	Baseline	25	25%	Baseline	5	6%	Baseline	8	10%	Baseline	8	10%	Baseline
Urban	35	45%	2.1 (0.9 – 4.7)	29	37%	1.6 (0.7 – 3.8)	17	27%	12.3 (2.2 – 67.5) <sup>†</sup>	16	25%	4.2 (1.2 – 14.6) <sup>†</sup>	16	25%	4.2 (1.2 – 14.6) <sup>†</sup>
<b>Limitation type<sup>*</sup></b>															
Seeing	17	35%	1.6 (0.7 – 3.9)	14	29%	1.1 (0.5 – 2.7)	-	-	-	-	-	-	-	-	-
Hearing	15	36%	1.5 (0.6 – 3.9)	10	24%	1.0 (0.4 – 2.5)	-	-	-	-	-	-	-	-	-
Mobility	34	44%	2.3 (1.0 – 5.4)	35	45%	2.5 (1.1 – 5.7) <sup>†</sup>	-	-	-	-	-	-	-	-	-
Memory	16	36%	0.9 (0.4 – 2.2)	12	27%	0.6 (0.3 – 1.7)	-	-	-	-	-	-	-	-	-
Self Care	18	49%	1.8 (0.7 – 4.8)	20	54%	3.6 (1.4 – 9.6) <sup>†</sup>	-	-	-	-	-	-	-	-	-
	12	46%	2.3 (0.8 – 6.6)	8	31%	1.1 (0.4 – 3.4)	-	-	-	-	-	-	-	-	-
<b>Communication</b>															

<sup>\*</sup>People with disabilities only

<sup>†</sup>p<0.001 or <sup>†</sup> p<0.05 multivariate logistic regression

### 3. Results

#### 3.1. Disability and incontinence

814 people with disabilities and 702 people without disabilities were recruited into the case-control study. Of these, 179 people with disabilities and 148 people without completed the revised incontinence module, and are included in these analyses (Table 2). 45% of people with disabilities and 21% of people without disabilities who completed the module reported either urine or faecal incontinence. People with disabilities were three times more likely to experience urinary incontinence, compared with people without disabilities (age, sex, location and socio-economic status adjusted odds ratio [Adj OR] 3.3, 95% Confidence Interval 1.8 – 5.8). People with disabilities were also twice as likely to report faecal incontinence (adj OR 2.3, 95% CI 1.3 – 4.0). On average, people with disabilities who experienced incontinence reported an interference level of 4.7 (3.9 – 5.5)/10 for urine incontinence and 5.1 (4.3 – 5.8) for faecal incontinence. Scores were similar for people without disabilities, with no significant differences (p>0.05) in the mean reported level of interference of either urine or faecal incontinence for people with disabilities compared to those without.

We explored predictors of experiencing urine or faecal incontinence among people with and without disabilities separately (Table 3). Among people with disabilities, urinary incontinence was more common in women than men (Adj OR 3.1, 1.5 – 6.6), and faecal incontinence was more common among people with mobility (2.3, 1.0 – 5.4) and self-care (3.6, 1.4 – 9.6) impairments com-

pared with other limitation types. Among people without disabilities, having either urine (12.3, 2.2 – 67.5) or faecal (4.2, 1.2 – 14.6) incontinence was more common in Luganville rather than rural settings, but there were no differences by sex or age group. Reasons for this were not explored through qualitative data collection.

People with and without disabilities in the qualitative in-depth interviews reported that incontinence disturbs sleep and is most disruptive at night. Participants explained that the urge to urinate or defecate did not always wake them, or that they often needed to urinate at night, but were unable to reach the toilet meaning they soiled their bedding and clothing.

*“This is mainly at night. Managing in the daytime is fine because its daylight and you’re just walking around, you’ll be awake and when the slightest urge gets upon you, you just get up and go. But it really disturbs you in your sleep when the urge is at night”* (Harry, no disability, 31-64 years).

All participants, and caregivers tried to manage incontinence by limiting drinking water.

*“When I drink too much water, then I’ll urinate too much and my wife gets angry because she already washed for me”* (Ron, disability, 31-64 years).

#### 3.2. The role of household facilities

##### 3.2.1. Water

People with mobility and self-care impairments in the qualitative component reported the most challenges when accessing wa-



**Figure 1.** Assistance using the family latrine.

Fred Sewen's photo caption: Accessing the toilet is impossible, unless I have someone to assist me.

ter to bathe and do laundry after leakage, because they lacked the physical strength, could not lift or balance the water container, or were unable to see the container. One participant with a disability, explained that his difficulties walking means he is reliant on others to collect his water.

*"At the moment it's very difficult to walk to the water source as I can't stand up. I just sit down full day and night and that's all I do, is just sit down and can't do anything"* (Duncan, disability, 31-64 years).

### 3.2.2. Sanitation

Without assistive technologies or accessible latrines, people with disabilities were reliant on caregivers for assistance and at increased risk of not reaching the toilet in time: *"If the relatives are outside, then I'll have to call them to come and assist me to take me to the toilet"* (Duncan, disability, 31-64 years). Through PhotoVoice, Fred Sewen (who has a disability) depicted his reliance on another



**Figure 2.** Accessible family latrine.

George's photo caption: I use this toilet. It supports me more than the first one. It supports me in everything

to take him to the family latrine (Figure 1). Of the five images taken, Fred ranked this as the most important issue for him.

Conversely, George has a wheelchair and an accessible latrine at home which he can use independently (Figure 2).

Many people with and without disabilities involved in the qualitative study explained how they were unable to reach the latrine before needing to defecate or urinate, and very few participants had a bed pan, urinal or commode. Management strategies applied included urinating next to the house, defecating in bed or using a bucket latrine. Dora (no disability, 31-64 years) explained how she is often unable to reach her latrine in time:

*"When I feel it come, I have to hurry. But the room I'm in is a long way from the toilet. I start walking out of my door, but I can feel it coming already. I have to hurry up to reach the toilet, even though its already running down"*.

Some people who experienced both faecal and urinary incontinence reported that the former is a greater challenge because it is easier to urinate in the open.

*"I think it's defecation. Because when she needs to urinate, she can just go outside, crawl to the grass and urinate. But since it takes time to get to the toilet (to defecate), she can accidentally go and make a mess on herself"* (Proxy interview for Edith, disability, 31-64 years).

Bucket latrines were used at night for people unable to reach the toilet in time, as explained by Sheila, who does not have a disability (aged 65+).

*R: I'm using [a bucket] because if I want to go outside, I have to be quick and the urine just runs.*

*P: So you need to urinate, so you just use this bucket... you just use it at night?*

*R: Yes, just at night.*

*P: So during the day you'll go (to the toilet)?*

*R: Yes, during the day I go to the toilet. I haven't told anyone about it.*

Bucket latrines, placed next to the person's bed, were used throughout the day and night by those who were unable to sit unaided out of bed. This is depicted in Selina's photo (Figure 3). Selina took five photos during PhotoVoice, and ranked this as the third most important issue, after being reliant on a caregiver and being unable to easily go outside and 'enjoy nature and breathe fresh air'.

During the qualitative study, we met a caregiver of Edith (31-64 years), who has a disability and experiences faecal and urinary incontinence. Edith's family were unable to care for her so sent her

**Table 4**  
Management Strategies among people who experience incontinence: comparing between people with and without disabilities<sup>o</sup>

	People with disabilities n %	People without disabilities n %	Age, Location, SES adj Odds Ratio (95% CI)
<b>Urinary Incontinence</b>			
<b>Able to wash and change in privacy whilst at home</b>	n=61 36 59%	n=22 20 91%	0.1 (0.1 – 0.6) <sup>†</sup>
<b>Missed out on social activities</b>	34 56%	6 27%	2.7 (0.9 – 8.6)
<b>Missed out on eating with others</b>	23 38%	3 14%	3.6 (0.9 – 14.7)
<b>Product Used in case of incontinence</b>			
Toilet Paper	10 16%	4 18%	Baseline
Homemade cloth or pad	14 23%	6 27%	0.7 (0.1 – 4.1)
Commercial cloth or pad	5 8%	0 -	-
Other	5 8%	0 -	-
Nothing	27 44%	12 54%	0.6 (0.1 – 2.9)
<b>Faecal Incontinence</b>			
<b>Able to wash and change in privacy whilst at home</b>	n=54 35 65%	n=24 24 100%	-
<b>Missed out on social activities</b>	20 37%	4 17%	3.8 (1.0 – 14.8)
<b>Missed out on eating with others</b>	21 39%	8 33%	1.4 (0.4 – 4.3)
<b>Product Used in case of incontinence</b>			
Toilet Paper	21 39%	14 58%	Baseline
Homemade cloth or pad	10 19%	3 13%	2.9 (0.6 – 14.8)
Commercial cloth or pad	7 13%	0 -	-
Other	3 6%	0 -	-
Nothing	13 24%	7 29%	0.7 (0.2 – 3.3)

<sup>o</sup> Using binary cut off of at least once a week and at least a small amount of either urinary or faecal incontinence experienced; Reference odds for binary variables are the inverse of presented odds; Where cell counts of zero prevent calculation of proportions and adjusted odds ratios, this is notated with “-”

<sup>†</sup>p<0.001 or <sup>+</sup> p<0.05 multivariate logistic regression



**Figure 3.** Bucket latrines.  
Selina's photo caption: Eating, bathing and toileting in the same room is unhygienic

to live on her own in a rural area, in a house without a water supply, latrine or bathroom. Edith defecates and urinates in the same room that she sleeps in. Her caregiver, who visits Edith as often as possible to bathe her, does her laundry and cleans her home, explained that Edith regularly has stomach cramps and worms.

*“When her stomach is really sore, she has worms come out... sometimes they come out of her mouth, and sometimes out of her bum”* (Proxy interview with Edith's caregiver).

**3.2.3. Hygiene**

Among people with either urinary or faecal incontinence in the quantitative study, people with disabilities were far less likely to be able to wash and change in privacy while at home, than people without (Table 4). People with disabilities were also more likely to miss either social activities or eating with others on account of their incontinence, although these findings were not statistically different. In the qualitative study, Duncan explained:

*“When there's a lot of people around, they would have to conceal me with calicos [cloths] just so I can shower. After shower then she removes the calicos, but I don't use the bathroom”* (Duncan, disability, 31-64 years).

Edith's caregiver said that: *“when she wants to bathe, she just crawls and bathes outside – it's not secure and there is no privacy”*.

Through PhotoVoice, Fred Sewen depicted how difficult it is for him to bathe because he has nothing to sit on. Instead, he stands, holding wooden bars, whilst his wife bathes him (Figure 4).

**3.2.4. Access to incontinence products**

Approximately half of participants with (44%) and without (54%) disabilities in the quantitative study did not use any products to manage urinary incontinence. Of those who experienced faecal incontinence, 39% of people with, and 58% of people without disabilities used toilet paper when they leaked (Table 4).

People with and without disabilities in the qualitative study, were either unaware of incontinence products available on the local market (e.g. mattress protectors, adult sized diapers), preferred to wash bedding and clothing frequently instead of using products, or felt they were prohibitively expensive. Some participants made their own products, including a handheld urinal by cutting the top off a plastic bottle, or a mattress protector by cutting a large plastic bag and laying it flat on the bed.

**3.2.5. Access to assistive technologies**

Access to assistive technologies, such as glasses, hearing aids, wheelchairs and communication device, was low among people with disabilities. Table 5 shows that many people with disabilities reported needing, but not having access to glasses (36%), hearing aids (20%), wheelchairs (17%) and walking sticks (16%). Less than 10% of people with disabilities used any type of assistive technology.

In the qualitative interviews, caregivers who supported people with self-care and mobility impairments described having to manually move the person, as none had lifting devices.

*“If he's [husband's] not here, and she needs to bathe or has soiled her underwear and I need to take her to the bathroom to wash her. If she moves a bit and I don't have the strength, we'll both fall down, and then I struggle to lift her up. [...] Because she's really heavy. When she eats... if she's happy about the food, she'll eat so much!”* (Proxy interview for Maddie, disability, 18-30 years).

**Table 5**  
Access to assistive technology amongst people with disabilities (n=179)

	Use device / technology		Have but don't use device		Need but don't have device		Neither have nor need device	
	n	%	n	%	n	%	n	%
Glasses	10	6%	5	3%	65	36%	97	54%
Hearing Aid	0	-	2	1%	35	20%	140	78%
Wheelchair	12	7%	2	1%	30	17%	133	74%
Crutches	7	4%	2	1%	20	11%	148	83%
White Cane	1	<1%	1	<1%	7	4%	168	94%
Walking Stick	9	5%	2	1%	29	16%	137	77%
Standing Frame	1	<1%	3	2%	21	12%	152	85%
Prosthesis	3	2%	0	-	6	3%	168	94%
Communication device	3	2%	0	-	27	15%	147	82%

Missing data for 2 participants

Disability service providers also highlighted the issue of limiting a person with a disability's food intake and cited a lack of incontinence products as a possible root cause.

*"And I see it as a problem when I visit [Cerebral Palsy] patients, that maybe... they all seem to be starving to death, because part of it is that the more they feed, the more they go to the bathroom. I don't think it's done in any kind of malicious way, I just think it's... you know, as the child gets heavier and heavier, so they feed just such a small amount and part of it is because resources are limited for diapers and things"* (Focus group discussion with Organisations of Persons with Disabilities).

### 3.2.6. Stigma and taboo

There is no word for incontinence in Bislama. Research participants did not speak about incontinence with friends, family or medical professionals. Reasons given in in-depth interviews included fear of what others would say or think of them, the belief that incontinence is a normal part of ageing, and that they had never been asked about it. David's caregiver explained why she has not spoken to healthcare staff about his incontinence.

*"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 for David, disability, 18-30 years).

Healthcare workers explained how difficult it was to discuss such sensitive topics, such as incontinence with patients. One explained that incontinence is the 'family's business' so is managed through those networks, but another welcomed the opportunity to discuss incontinence with the researchers.

*"I'm glad that we talked about this topic because I hope it can cause some ripples for somebody out there to stop us pretending that everything is fine"* (Healthcare worker).

### 3.2.7. Limited participation and wellbeing

People without disabilities in the qualitative study were able to manage their incontinence independently, though with difficulty. People with disabilities, especially those with cognitive, mobility and self-care impairments, required assistance to manage incontinence. People with and without a disability, who were reliant on caregivers, identified this as a major challenge, increasing with age. For instance, many individuals felt they were a burden to their caregivers, and some caregivers thought the same. Consequently, many people who experienced incontinence often managed it silently. Dora explained that she used to ask her daughters to help her do her laundry after she had soiled herself, but as her urinary incontinence became more regular, they became tired of assisting her.

*"I won't say much - I don't want to explain it to them because even if I tell them, they still won't take notice of me"* (Dora, no disability, 31-64 years).

Adult children of ageing parents who had incontinence, faced competing demands on their time, including working and supporting their own children. Some viewed their parents as a burden, which could result in neglect.

*"[He] had a child, and then when he got married, he left and they put me in this house [alone]"* (Doris, disability, 65+ years).

Similarly, Ron (disability, 31-64 years) reported that his family no longer bought him soap. Though he did not know why, he stated that *"they've been looking after me for a long time; they're probably tiring of me"*.

Many participants felt a deep sense of shame when family members supported their toileting. For instance, this led Jane to tell her adult son to stop assisting and instead relied on her four-year-old son to care for her.

*"Don't come close to me anymore, you'll just come close when... I need you when I'm hungry. But to come and help me with the toilet, I explained that because I've become like a child again, you'll have to step away from me"* (Jane, disability, 31-64 years).

Participation in daily life, such as going to church, visiting friends, going to the local market or town, was often self-limited or limited by caregivers. For people with disabilities, caregivers wished to protect them from disability discrimination. Simon's caregiver explained that they no longer take him out of the home because he had been teased and socially excluded in the past.

*"People stare down on him whenever we attend such functions and laugh at him and so it makes me sad"* (Proxy interview for Simon, disability, 18-30 years).

With a lack of access to assistive technologies, leaving the home was particularly difficult for people with disabilities and their caregivers, as depicted by Selina in (Figure 5).

Many participants and caregivers limited participation because of a lack of public toilets and a fear of soiling themselves in public. If people did venture outside, they did not stay out as long as they wanted to. Those with financial resources had a greater degree of mobility as they could afford a car or a taxi to take them home quickly, but they found this stressful. Many decided to remain at home.

*"When there is something happening at [location], I cry about it, because I can't go. Even to go to town. If I want to go, I have to go quickly in a vehicle - just go and come back quickly. If I stay too long, it will be a problem"* (Jackie, no disability, 31-64 years).

*"If I was in public and were to urinate, it'll look bad because if it occurs. I don't know how am going to do it because of the pub-*



**Figure 4.** Inaccessible bathing facilities.  
Fred Sewen's photo caption: Having a bath is hard work



**Figure 5.** Reliance on caregivers  
Selina's photo caption: It's challenging to enjoy nature and breathe fresh air

*lic and I'm ashamed to have the public witness something like this from me. It is better I remain isolated and take care of myself separately from everyone"* (Duncan, disability, 31-64 years).

#### 4. Discussion

Our results showed that incontinence was an incredibly taboo topic: people who experience it do not talk about it to others, including medical professionals. Our quantitative results were limited on account of this, with smaller sample sizes than anticipated and limited power in our analyses as a result. With a lack of affordable incontinence products and inaccessible WASH facilities at home and in public settings, people manage privately and inadequately. Many participants limited their social interactions and lived in relative isolation. People with disabilities faced additional barriers including disability discrimination, inadequate access to assistive technologies, such as wheelchairs, and felt as though they were a burden to caregivers. Some caregivers felt the same and this was compounded by a lack of lifting devices, which became more

critical as a young person with a disability and incontinence grew up and became heavier.

Our findings on the proportion of people with and without disabilities who experience faecal or urinary incontinence reflect existing evidence. For instance, urinary incontinence prevalence rates span from 5-70%, with the majority of studies identifying the average prevalence between 25-45% [35]. Analyses of 38 prevalence studies of faecal incontinence noted a median prevalence of 7.7% [36].

People who experience incontinence, require greater access to water, sanitation and hygiene for toileting and personal hygiene, but our study shows that the quality of access is lower for this group. This is apparent in other settings, where evidence shows that people with disabilities commonly face barriers to access including inaccessible routes to water points and latrines, coming into contact with urine and faeces, a lack of support structures inside latrines to enable independent access and a reliance on caregivers to collect water, support toileting and the maintenance of personal hygiene ([8, 37-39]). Such challenges are exacerbated by

inadequate access to assistive technologies, such as wheelchairs, so participants with mobility limitations may be reliant on caregivers to take them to the toilet. This is compounded by a lack of access to incontinence products, such as bedpans, mattress protectors and incontinence underwear. Management strategies applied included using bucket latrines, which pose a significant health risk to the participant and their family: if these are uncovered, household members are exposed to pathogens in the faeces, which can result in typhoid, diarrhoea and cholera. Bucket latrines are also unsafe to use as the person can injure themselves falling off. Accessible sanitation, including commodes, covered bedpans and urinals can support people with incontinence to manage more effectively and safely.

A lack of assistive technologies and incontinence products also have a negative impact on caregivers, who may have to physically support the individual to reach the toilet, relieve themselves in bed and bathe. Without lifting devices, caregivers can suffer from back and associated difficulties, emotional and physical exhaustion and frustration [40, 41]. In our study, this was particularly challenging for ageing caregivers as their children grew and became heavier. To cope, some caregivers limited the person's water and food consumption so that they would not need to urinate or defecate so often and would remain light enough to manoeuvre. Existing evidence also reports that people with mobility impairments, including those with cerebral palsy, are at a greater risk of malnutrition, though this is associated with difficulties feeding rather than to limit weight gain [42, 43].

Older people with and without disabilities, who experience incontinence often relied on their children to support them with self-care activities. However, their children often worked, and had children of their own to support. These competing demands on caregivers' time and increasing support requirements from ageing parents can mean the older person is viewed as a burden, which can lead to neglect or abuse [41]. Consequently, disability, incontinence and ageing discrimination, as well as inadequate WASH services, interconnect to compound limitations on levels of participation (self-imposed, or imposed by caregivers) that inhibit a person's ability to thrive [44]. This supports Amartya Sen's assertion that limited opportunities can harm an individual's expectation of what they can achieve, as well as altering how others interact with them [45].

The stigma surrounding incontinence was striking in our study, though it is present in other settings, including in Pakistan where there is also no word for incontinence [46], and in Ethiopia where people reported being shy to talk about it [47]. Arguably this stigma is borne from disgust associated with urine and faeces, particularly physical contact, as well as limited knowledge, information and skills about incontinence and its management. In our study, the private nature of incontinence management and care is demonstrated by healthcare provider's unwillingness to raise the issue with patients who clearly experienced it.

#### 4.1. Implications for further research, policy and practice

Our findings provide detailed information on incontinence as experienced by women and men with and without disabilities in the two most northern regions of Vanuatu. These results are not directly generalisable to the country as a whole, or beyond. However, the following actions can be used to highlight areas of further research, policy and practice to improve the situation for people with and without disabilities who experience incontinence across Vanuatu, and in other similar settings.

- Destigmatise incontinence by giving it a name in Bislama, and disseminate information about what causes incontinence, including the links between the diabetes epidemic and urinary

incontinence, management strategies, and where people can seek support. Enhance awareness and capacities of healthcare officials so they can speak about incontinence with patients, communicate effectively with people who have different impairments and effectively provide assistance.

- Develop reusable, sustainable and cost-effective incontinence products that meet the needs of people with different impairments, and make them available on the local market with clear and accessible information on the product design. Additionally, support caregivers to understand home based management strategies, including developing a regular toileting routine and training pelvic floor muscles, as well as making lifting belts and adult sized diapers .
- Develop sustainable and local production of assistive devices, such as commodes, bedpans and lifting devices to support people with disabilities and caregivers to manage incontinence.
- Integrate hygiene and incontinence management within water and sanitation related policies; without good hygiene behaviours, the benefits from water and sanitation infrastructure are restricted. Coverage of accessible and private latrines in public spaces, including schools, marketplaces and healthcare centres must be prioritised. These should include water, soap and mechanisms to dispose of incontinence products, and water supplies. Any policy discourse, development and implementation should be led by Organisations of Persons with Disabilities so that people with disabilities are at the front and centre, reinforcing the statement "Nothing About Us Without Us".
- Invest resources in exploring culturally appropriate and acceptable ways to capture data on incontinence in repeated surveys such as Demographic and Health Survey (DHS) or Multiple Indicator Cluster Surveys (MICS). Use these as standard to build the evidence base on incontinence, disability and WASH in the Pacific and elsewhere to generate a more comprehensive picture to drive policy change.

#### 4.2. Strengths and limitations

A key strength is that this research was a large, mixed methods study including a two-province census, as well as quantitative case control and in-depth qualitative components. This is the largest study globally to have explored disability, WASH and incontinence. We applied robust and validated methodologies, including the Washington Group Short Set, and questions on depression and anxiety and depression for adults, and the WHO/UNICEF JMP questionnaires on WASH ([31, 49, 50]). The research team developed qualitative and quantitative tools to capture incontinence in collaboration with an incontinence e-group with members including academics, medical professionals and practitioners, as these tools were unavailable.

A number of limitations must be considered when interpreting these results. There were several challenges surrounding the effective translation of pre-validated tools as many English words and concepts (including 'incontinence') do not directly translate into Bislama. To manage this, we translated the quantitative data collection tools from English to Bislama and back into English and provided in-depth training for enumerators in Bislama. Despite these measures, data collectors still struggled with the interpretation of key themes, so the qualitative research team provided refresher training during the quantitative data collection process in advance of data collection using the revised incontinence module. Our case-control incontinence sample was therefore smaller than anticipated, with potential limitations on statistical power, and gaps in geographical coverage as a result.

## 5. Conclusion

Incontinence is common in Vanuatu, and more prevalent for people with disabilities than those without. The majority of people who experience incontinence in our study were unable to access WASH facilities as often as required, and did not use incontinence products as these were either unavailable or unaffordable. Consequently, people with and without disabilities limited their participation in activities outside the home because of a fear of soiling themselves in public. Additionally, people with disabilities and caregivers faced disability discrimination and insufficient access to assistive technologies. This negatively affected participants' wellbeing and quality of life. Collective action must be taken to destigmatise incontinence, increase access to water, sanitation and hygiene facilities, incontinence products as well as assistive technologies required by people with disabilities and those that support them in LMICs.

## Contributors

JW: Literature Search, Study Conceptualization, Study Design, Data Collection Oversight, Verification of underlying data, Data Analysis, Data Interpretation, Manuscript Writing

CM: Data Collection Oversight, Data Interpretation, Manuscript Review

LB: Study Design, Data Collection Oversight, Data Interpretation, Manuscript Review

JT: Study Design, Data Collection Oversight, Data Interpretation, Manuscript Review

SB: Study Design, Data Interpretation, Manuscript Review

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JS: Data Collection, Data Interpretation, Manuscript Review

JL: Data Collection, Data Interpretation, Manuscript Review

RP: Study Design, Data Collection Oversight, Data Interpretation, Manuscript Review

IzM: Literature Search, Study Conceptualization, Study Design, Data Collection Oversight, Verification of underlying data, Data Analysis, Data Interpretation, Manuscript Writing

JW, IZM, PS and JT had full access to the full data in the study, and accept responsibility to submit for publication

## Data sharing statement

Access to an anonymised dataset for secondary analyses may be provided on reasonable request. Approval for all requests must be jointly provided by Vanuatu National Statistics Office, World Vision Vanuatu and the LSHTM before data can be shared.

## Declaration of interests

Jane Wilbur, Philip Sheppard and Islay Mactaggart reported grants from World Vision Vanuatu during the study. All other authors have nothing to declare.

## Declaration of Competing Interest

The authors declare no conflict of interest.

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