International Centre for Evidence in Disability

Australian Aid

VSPD Vanuatu Society for People with Disability

World Vision

London School of Hygiene & Tropical Medicine

Water For Women

DPA Advocating for rights & promoting abilities of people with disabilities since 1999

VNSO Vanuatu National Statistics Office Bureau National des Statistiques

Ministry of Justice & Community Services Government of Vanuatu

WATER, WOMEN AND DISABILITY STUDY

EXECUTIVE SUMMARY

MARCH 2020

ACKNOWLEDGEMENTS

We would like to thank the qualitative and quantitative team of field workers for their hard work, commitment and dedication to this project.

We would also like to acknowledge the support of the following agencies, associations and organisations for their extremely supportive roles throughout the planning and fieldwork stages of this study:

Vanuatu National Statistics Office
Ministry of Justice and Community Services
SANMA Provincial Government
TORBA Provincial Government
Vanuatu Disability Promotion and Advocacy Association
Vanuatu Society for People with Disabilities
CARE Australia/Vanuatu
The Vanuatu Civil Society Disability Network
Vanuatu Red Cross Society
World Vision Australia

INSTITUTIONS AND PERSONNEL

This study was conducted collaboratively between World Vision Vanuatu and the International Centre for Evidence in Disability at the London School of Hygiene & Tropical Medicine.

RESEARCH INVESTIGATORS:

- Luke Bambery, World Vision Vanuatu
- Ellis Lee, World Vision Vanuatu
- Jamie Tanguay, Vanuatu National Statistics Office
- Judith Iakavai, Vanuatu Society for Disabled People
- Dr. Islay Mactaggart, London School of Hygiene & Tropical Medicine (PI)
- Phil Shepherd, London School of Hygiene & Tropical Medicine
- Jane Wilbur, London School of Hygiene & Tropical Medicine

PROJECT PARTNERS:

The WWD study was carried out in partnership with Vanuatu National Statistics Office, Ministry of Justice and Community Services, Vanuatu Disability Promotion and Advocacy Association (VDPA), and Vanuatu Society for People with Disability (VSPD).

FUNDER:

The Water, Women, and Disability study and report was funded by the Australian Government's Water for Women Fund along with additional funding from the Australian NGO Cooperation Program (ANCP) and generous donations from the Australian public to World Vision Australia.

WORLD VISION VANUATU AND PARTNERS TECHNICAL TEAM:

Sally Baker, Martin Prichard (Technical Consultant), Aureliene Koko (VDPA), Judith Iakavai (VSPD), Janet Collins, Diana Dick, Kendra Gates Derousseau, Roger Kalatei, Vomboe Molly, Chloe Morrison, Relvie Poilapa and Kenson Tari.

QUALITATIVE RESEARCH TEAM:

Judith Iakavai (VSDP)
Sannine Shem (independent consultant)
Headley Aru (independent consultant)

QUANTITATIVE RESEARCH TEAM

Kerine Aisoh
Margueritte Andy
Nadia Arsen
Marco Axi
Jerry Baia (Team Leader)
Ritchie Baia
Doreen Bani
Jerina Bani
Reuben Bani
Daniel Boe (Team Leader)
Elken Donald
Alistair Eldads (Team Leader)
Franky Elijah
Jane Enock
William Garae
Luciana Goddin
Vanessa Godwin
Mario Jimmy
Torika Kalman (Team Leader)
Hosea Langi
Jemina Lonsdale
Esther Love
Lavinia Lulu
Jullianeta Malisa
Asley Maltock
Warren Maltock
George Marcel
Cecilia Masanga
Dickinson Mau
Allan Moah
Ricky Mol
Heather Molitambe
Belinda Morris
Nesther Nemtaken (Team Leader)
Linda Niltamate
Job Oliver (Team Leader)
Jerry Rojo (Team Leader)
Sonia Simeon
Valerie Solomon
Salome Sumbe
Rosemarie Taga
Geraldine Tamata (Team Leader)
Karen Tamata
Joyce Tari
Basil Tawera
Sandra Toa
Sonia Toa
Keithson True (Team Leader)
Laurenty Tsiabon
Anna Varegali
Veteho Viji
Solomon Wai (Team Leader)
Claudia Warsal
Lindi Wilkins
Barry Wobur
Timet Wola

01

EXECUTIVE SUMMARY

BACKGROUND

WATER SANITATION AND HYGIENE (WASH)

Safely managed drinking water, sanitation and hygiene (WASH) are essential to human health and well-being[1].

Access to WASH contributes to good health and the prevention of disease, enables participation in other areas of life such as livelihoods, school and training[2] and has social and economic impacts on individuals, as well as communities and nations[3].

WASH is a gendered issue, with women often bearing the socially prescribed responsibility for household water provision and providing WASH-related care to family members who require it[4]. Women and girls have additional WASH requirements related to menstrual hygiene management, and may be more at risk of incontinence.

Incontinence can be classified as faecal, urine, or both. Urinary incontinence is defined as the involuntary loss of urine that is objectively demonstrable, and is a social or hygienic problem[5,6]. Faecal, or bowel, incontinence is an inability to control bowel movements, resulting in the involuntary passage of stools[5].

Incontinence is a complex health and social issue that is largely taboo and widely overlooked. It is estimated that incontinence affects 1 in 4 women over the age of 35 years, and 1 in 10 adult men[7]. These figures are mostly from high-income settings and it is likely may be higher in Low and Middle Income Countries, although evidence is lacking. Incontinence affects a wide variety of people, particularly older people, mothers, children and persons with disabilities[5]. Incontinence also leads to additional WASH requirements, in part due to increased need to bathe and use the latrine, and can be extremely stigmatising – particularly when these WASH requirements cannot be met.

WASH DEFINITIONS

(Source: washdata.org)

Safely managed water is defined as drinking water from an improved water source (one which has the potential to deliver safely managed water supply by nature of its design and construction) which is located on premises, available when needed and free from faecal and priority chemical contamination.

Safely managed sanitation is use of improved facilities (those designed to hygienically separate excreta from human contact) which are not shared with other households and where excreta are safely disposed in situ or transported and treated off-site.

The presence of a handwashing facility with soap and water on the premises is the global priority monitoring indicator for hygiene.

PhotoVoice photo by James Packet captioned:

"I can bathe myself. I can do it myself. I'm proud to be clean"

WASH AND DISABILITY

Globally, there are an estimated 1 billion people with disabilities (approximately 15% of the world's population)[8].

People with disabilities commonly have less adequate access to WASH services than people without disabilities[9]. Within their homes, people with disabilities are less likely to have access to bathing and latrines, and face stigma and discrimination when using public WASH services[9].

WASH AND DISABILITY IN VANUATU

Vanuatu is a Pacific nation of 83 islands extended over 1000 kilometres that is considered one of the most vulnerable to natural disaster in the world[10 11].

Combined coverage of basic water and sanitation is lower in the Pacific than any other region, and lower in Vanuatu than many of its Pacific neighbours[12]. Less than half of ni-Vanuatu have access to safely managed drinking water, less than two thirds have access to at least basic sanitation and less than three quarters have a basic handwashing facility at home[13].

According to Vanuatu's 2009 Census, around 5 percent of the population were found to have a mild, moderate or severe disability[14]. This is lower than the often-stated global estimate of 15%, however more recent evidence has shown a wider range of estimates across different settings, and confirmed the historic impact of using non-standardised or impairment-based methodologies[8,15,16]

Vanuatu has demonstrated considerable commitment towards the rights of persons with disabilities and to gender equality. This includes ratifying the UNCRPD[14], establishing disability related strategies, action plans, and a Disability Desk within the Ministry of Justice and Community Services[14]. Additionally, the Vanuatu National Sustainable Development Plan 2016 – 2030 ("Vanuatu 2030: The People's Plan") formalises the Republic's commitments to the Sustainable Development Agenda and to disability and gender inclusive progress, including Economy Pillar Objective 2.2 "Ensure all people have reliable access to safe drinking water and sanitation infrastructure".

However, little rigorous evidence exists about people with disabilities' access to WASH services within Vanuatu and the impact of poor WASH access on women. Moreover, limited evidence exists globally on MHM and incontinence. The Water, Women and Disability Study was undertaken to address these gaps to inform programming, policy, and advocacy interventions.

The Water, Women and Disability study aimed to complete a comprehensive population-based study of disability in TORBA and SANMA Provinces, to measure how common disability is, and understand access to and experience of WASH, menstrual hygiene management (MHM) and incontinence amongst persons with and without disabilities with a gender lens.

Photovoice photo by Marie Chanelle captioned:

"I need a safe and private bathroom"

LAETEM DAK KONA

The Laetem Dak Kona (LDK) project, funded by the Australian Government's Water for Women Fund, will be implemented by World Vision Vanuatu with and through its key partners in the two northern provinces of Vanuatu, SANMA and TORBA from 2018-2022. LDK aims to achieve improved health and well-being for people with disabilities and women in these provinces through access to gender-equitable and disability-inclusive WASH systems.

The Water, Women, and Disability (WWD) study in SANMA and TORBA provinces provides the baseline for LDK, including disseminating findings at all levels in an accessible way, to inform the development of the intervention.

METHODOLOGY OVERVIEW

1. Complete household listing and disability prevalence survey across almost 55,000 individuals in TORBA and SANMA Provinces (March to July 2019).

- The Washington Group Short Set of questions[i] were used to identify people with disabilities. Adults aged 18+ self-reported, and adult caregivers reported for all children 5 – 17 (children aged 0-4 years were excluded from disability screening)

2. A nested quantitative case-control study of people with and without disabilities (sample size 800 women and men with disabilities, and 800 women and men without).

3. An in-depth qualitative study of menstrual hygiene and incontinence (46 individuals with and without a disability, and 17 policy makers and implementers focusing on WASH, health and disability).

Quantitative data was collected by a team of 48 data collectors and five field supervisors, and the qualitative team consisted of five people.

Gender composition and meaningful inclusion of persons with disabilities in all teams was taken into account when recruiting. Teams were trained to use the data collection tools correctly, carry out research ethically with people with disabilities and how to discuss sensitive topics such as MHM and incontinence.

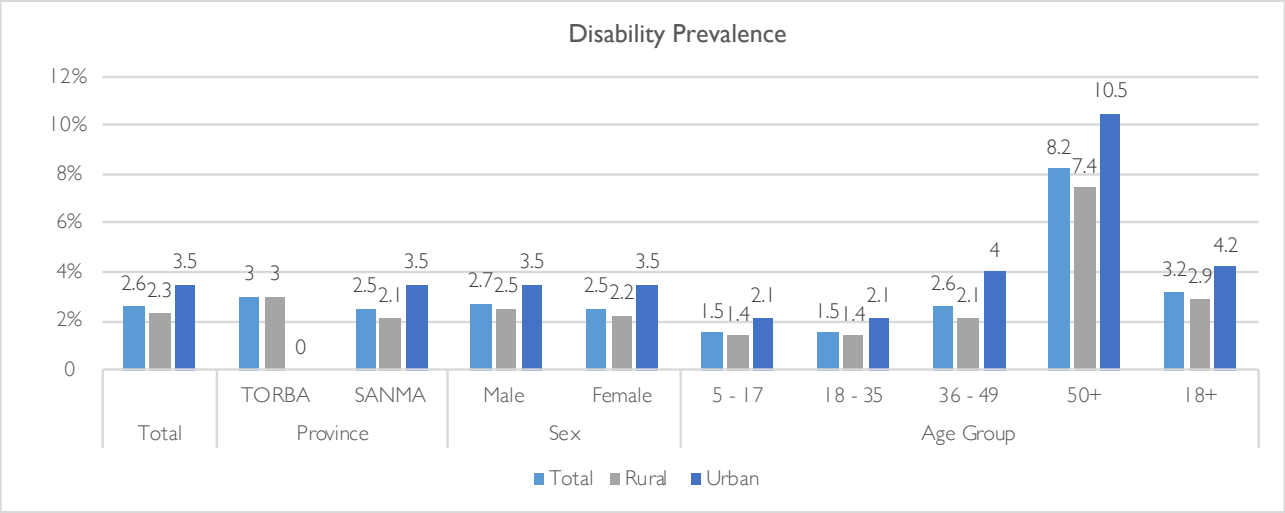
Data collection tools were translated from English to Bislama, piloted and refined prior to data collection. Full ethics approval was granted by the London School of Hygiene and Tropical Medicine (LSHTM) and endorsement was provided by the Ministry of Justice and Community Services.


Photo Credit: Mike Kaun (WVV)

i A self-reported functional limitation tool developed by the United Nations Washington City Group. Four additional questions on Anxiety and Depression were also captured (ESF-Lt) but not included in prevalence estimates http://www.washingtongroup-disability.com/

KEY FINDINGS[ii]

DISABILITY PREVALENCE

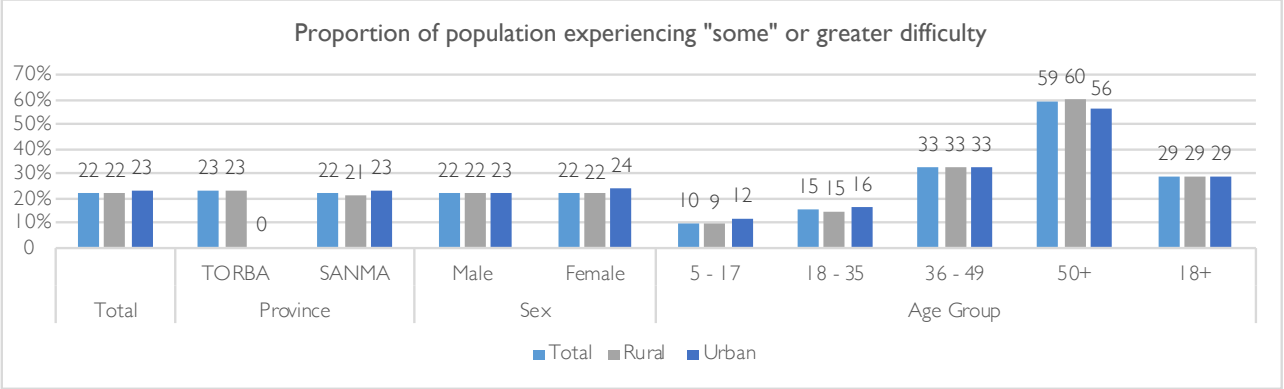


ES Graph 1: Disability Prevalence

- All-age disability prevalence using the standard Washington Group definition was 2.6%, increasing to 3.5% in Luganville. This is lower than estimates using the same tool in different settings, but comparable to other Pacific estimates (e.g. 2.7% in Samoa, 4.6% in Tonga, 3.1% in Kiribati Census and 2.4% in Palau)[17-20]. There may be cultural reasons which affect reporting of functional limitation in this region which warrant further qualitative research.

- As seen in other settings, disability increased with age, but was similar by sex[16].

- The proportion of people not categorised as having a disability, but reporting "some" difficulty in functioning was 22% (ten times higher than the prevalence of disability).



ES Graph 2: Proportion of population experiencing "some" or greater difficulty

ii All findings reporting differences between groups are statistically significant at the 95% confidence level. The study's Full Report contains a complete statistical appendix.

WATER AND HYGIENE

- 91% of households overall had access to an improved water supply[iii], although this was lower in rural households (89%) compared to urban (99%).

- The majority of households (86%) do not have a water source on the premises, but it takes less than 30 minutes (round trip) to collect water.

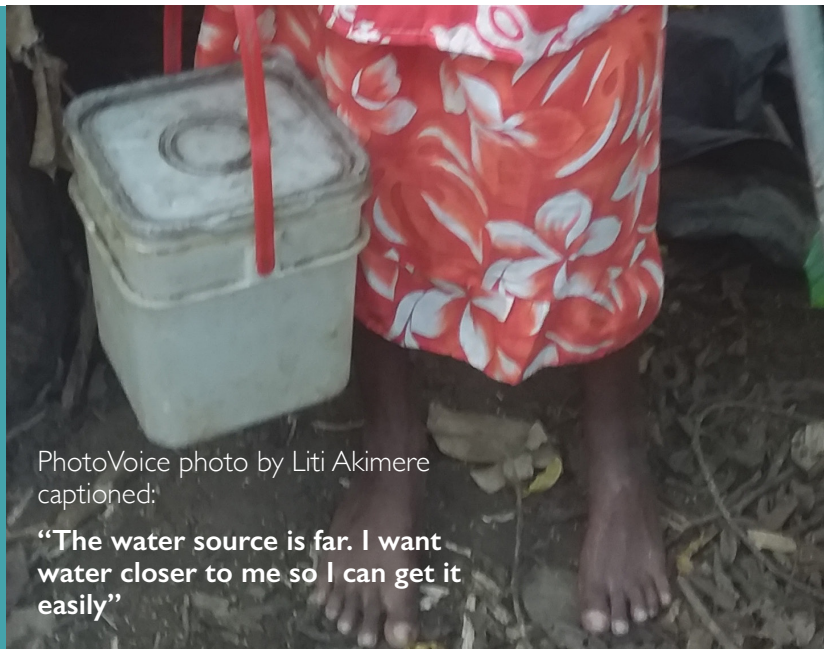
- Women and men with disabilities were less likely to collect water themselves than women and men without disabilities. Less people with mobility limitations reported feeling safe when doing so, citing distance to the water source, fear of abuse from others, and inaccessibility of terrain as reasons. Menstruating women reported an increased requirement for water.

- People bathed most regularly using water from a pump or standpipe outside the dwelling but inside the household compound, but 19% of people with disabilities used a different bathing source to other household members.

- Harmful menstrual beliefs and taboos were prevalent, and internalised by women and girls. The most widespread beliefs were that menstruating women and girls will kill crops if they touch them, they must not work in the gardens, cook food, or lift heavy objects. They must also collect their own water for bathing and washing their reusable menstrual product, wash their own menstrual product and use separate latrines and bathing shelters.

- Women and girls with a disability who require support to collect water, bathe, and do the laundry, are more negatively affected by harmful menstrual beliefs. This is also true of people who have difficulties accessing the latrine or bathing shelter.

Water availability was insufficient (not available every time needed in last 3 months) for over half of all households (57%), with no difference between rural and urban locations.



PhotoVoice photo by Liti Akimere captioned:

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

SANITATION

- 55% of households had access to an improved sanitation facility[iv], with no difference depending on whether there was a person within the household with a disability or not.

---

iii **Improved drinking water source definition:** those that have the potential to deliver safe water by nature of their design and construction, and include: piped water, boreholes or tubewells, protected dug wells, protected springs, rainwater, and packaged or delivered water.

iv **Improved sanitation facilities definition**: those designed to hygienically separate excreta from human contact, and include: flush/pour flush to piped sewer system, septic tanks or pit latrines; ventilated improved pit latrines, composting toilets or pit latrines with slabs.

- Amongst people with disabilities, 14% did not use the same facility as other members of their household, and 38% needed assistance to use the toilet.

- 32% of people with disabilities found it difficult to use the toilet without coming into contact with faeces or urine. This was more likely for older people, and people with mobility and self-care limitations.

Inaccessible latrines are a more significant challenge for people who experience incontinence, as they need to reach a toilet quickly. This indignity affects a person's ability to leave home and participate fully in daily life.

- People with mobility, self-care and remembering functional limitation were least able to use the toilet as frequently as they desired.

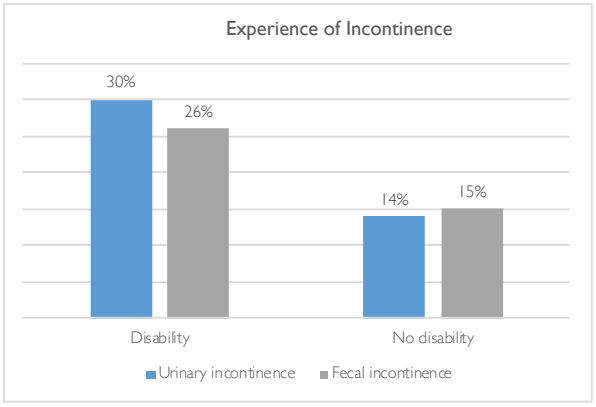
- Participants with disabilities cited the distance to the latrine, unsafe route to reach it, lack of lighting and privacy as major barriers. Older people and people with mobility limitations said that a lack of support structures inside the toilet made it difficult or impossible to use.

- Barriers caused by inaccessible latrines are compounded by the lack of affordable incontinence products on the market, such as bed pans and adult diapers, and information about management strategies.

- Management strategies applied by people who experience incontinence and are unable to sit unaided out of bed, include uncovered bucket latrines next to their bed, which are emptied and cleaned by carers.

Photovoice photo by Edline Elton captioned:

"Eating, bathing and toileting in the same room is unhygenic"



ES Graph 3: Incontinence

- Waste water from bathing a person who experiences incontinence, can be thrown on the ground outside the home, and without water on the premises, some carers wash the person who experiences incontinence's laundry in the creek.

- People with disabilities were twice as likely to experience incontinence as people without. Women with disabilities and people with mobility limitations reported a greater likelihood of experiencing urinary incontinence than other people with disabilities. No sex difference was recorded for faecal incontinence.

- Participants with and without a disability who experienced incontinence, reported that it disturbs sleep and affected them most during the night. Management strategies applied by all participants who experience incontinence, included limiting water intake with and after the evening meal.

- Carers reported limiting people's consumption of food and water, in order to reduce the number of times the person needs to urinate, and to manage weight gain. This was a particularly concern for ageing parents of growing children with mobility functional limitations, who have no lifting devices.

STIGMA AND TABOO

There is no word for incontinence in Bislama, and most people who experience incontinence do not talk to others about it, preferring to 'manage' as independently as possible. This was borne from shame, a fear of what others would say and think, because it is thought of as a normal part of ageing and because they have never been asked about incontinence by a medical professionals or members of the family.

There were very few accounts of formal education in school about puberty and menstruation, a dearth of accurate information on the menstrual cycle, how to manage it hygienically, and how to dispose of menstrual products in an environmentally friendly way.

Information that was provided focused on menstrual taboos and restrictions, and practical management of menstruation, such as using a menstrual product to soak up menstrual blood, but not how often to change the product.

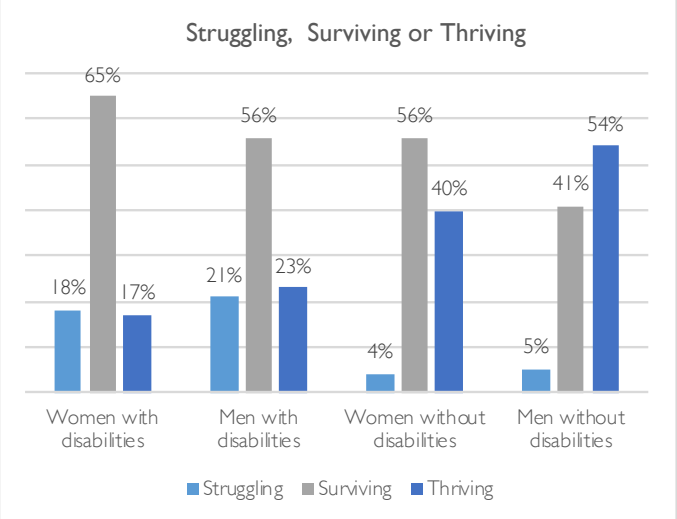
Key influencers for menstrual hygiene are mothers, older sisters and grandmothers. Some participants were told menstruation is normal, but it was always framed negatively as a 'problem' or 'women's sickness'. The negative language used to describe menstruation shows how menstrual taboos are passed down the generations.

SURVIVING VERSES THRIVING

Based on self-reported satisfaction with life and Gallop World Poll cut-offs[21], people with disabilities were more likely to be struggling and less likely to be thriving than people without disabilities. Women with disabilities were the least likely to be thriving.

People with and without a disability who experience incontinence cited a reliance on others as a major challenge, partly because of a deep sense of shame they feel when a carer supports them with toileting. Women and men who experience incontinence felt they were a burden to their families and carers, and some carers felt this too, which led people to try to manage their incontinence silently.

Healthcare workers reported a lack of capacity for development and skills training on providing services for people with disability and limited understanding of incontinence and disability and menstrual hygiene



ES Graph 4: Struggling, Surviving or Thriving

There were many accounts across all participants who experience incontinence of limiting their own participation, with a lack of public toilets and fear of soiling oneself being cited as a major concern. Carers also limit people with disabilities movements for these reasons, and because they do not want the person subjected to ridicule by others.

Women with a disability were also more likely to restrict their participation when they are menstruating than women without a disability.

STUDY RECCOMENDATIONS FOR WASH ACTORS IN VANUATU

IN TORBA AND SANMA:

- Continue to work with stakeholders to strengthen consistency of household water supply in TORBA and SANMA - without this fundamental WASH building block in place, women and men with and without disabilities will continue to face WASH challenges.

- Prioritise self-supply initiatives within the WASH programmes, especially targeting households with persons with disabilities, all older people and anyone experiencing incontinence.

- For both MHM and incontinence management: Explore locally available, reusable, sustainable and cost-effective materials that can be used to make environmentally-friendly products that meet potentially different requirements of people with different impairment types.

- Support carers to understand incontinence and management strategies that can be applied at home, and how to support another person to manage their menstruation hygienically and with dignity.

- Complete accessibility and safety audits for all clients with disabilities and for all public facilities - remember, one size does not fit all in terms of WASH and disability.

- Feed into current rural and urban sanitation plan development, by encouraging and working with stakeholders to develop building regulations to ensure accessible public facilities (with bins with lids in female toilets for MHM) are built in both rural and urban settings.

ACROSS VANUATU:

- Destigmatise incontinence by giving it a name in Bislama and providing clear messaging to communities around what it is and where people who experience it can get support.

- Destigmatise menstruation by celebrating it, challenging harmful beliefs and avoiding euphemisms.

- Champion hygiene as a core component of WASH activities, including capacity to bathe regularly with soap - this is particularly important for women and girls who menstruate.

- Encourage stakeholders to build MHM, incontinence and disability into healthcare worker training, including how to discuss sensitive topics such as incontinence with people who experience it, and the links between urinary incontinence and the diabetes epidemic.

- Encourage and work with Ministries to develop a single, comprehensive and fully inclusive Water, Sanitation and Hygiene Policy that explicitly includes people with disabilities, MHM and incontinence.

- Prioritise household level water supply in national strategic planning.

- Work with Disabled Peoples Organisations to support full and meaningful inclusion of people with disabilities, and diminish attitudinal, institutional and structural barriers to participation that become internalized by people with disabilities.

To ensure no one is left behind, these recommendations (designed to inform the LDK intervention) should be taken forward by all WASH actors in Vanuatu.

Photo Credit: World Vision

REFERENCES

1 World Health Organization. WHO Water, Sanitation and Hygiene strategy 2018-2025. (World Health Organization, 2018).

2 World Health Organization. UN-Water global analysis and assessment of sanitation and drinking-water (GLAAS) 2017 report: financing universal water, sanitation and hygiene under the sustainable development goals. (2017).

3 Mara, D., Lane, J., Scott, B. & Trouba, D. Sanitation and health. PLoS medicine 7, e1000363 (2010).

4 Kayser, G. L., Rao, N., Jose, R. & Raj, A. Water, sanitation and hygiene: measuring gender equality and empowerment. Bull World Health Organ 97, 438-440, doi:10.2471/BLT.18.223305 (2019).

5 Giles-Hansen, C. Hygiene needs of incontinence sufferers. (Available From: https://www.ircwash.org/sites/default/files/hygiene_needs_of_incontinence_sufferers_sept2015_final.pdf, 2015).

6 Ali, H. S., Lakhani, N. A. & Sarwar, N. G. URINARY INCONTINENCE THREE MONTHS AFTER DELIVERY. The Professional Medical Journal 20, 530-536 (2013).

7 Abrams, P., Cardozo, L., Wagg, A. & Wein, A. in 6th International Consultation on Incontinence, Tokyo, September 2016.

8 World Health Organization. World report on disability 2011. (World Health Organization, 2011).

9 Nations, U. Disability and Development Report: Realizing the Sustainable Development Goals by, for and with persons with disabilities. (2018).

10 Mackey, B. et al. Vanuatu Ecosystem and Socio-economic Resilience Analysis and Mapping (ESRAM). (Apia, Samoa, 2017).

11 Morrison, A. An Evaluation of a World Vision Water, Sanitation, and Hygiene (WASH) Project in Tanna, Vanuatu, University of Otago, (2016).

12 United Nations Children's Fund (UNICEF). A snapshot of Drinking Water and Sanitation in the Pacific - 2017. (Available from: https://www.unicef.org/EAPRO_Pacific_Snapshot_Final_2017_27_10_2017.pdf, 2017).

13 United Nations Children's Fund (UNICEF) & World Health Organization. Progress on household drinking water, sanitation and hygiene 2000-2017: Special focus on inequalities. (2019).

14 UNICEF Pacific and Vanuatu National Statistics Office. Children, women and men with disabilities in Vanuatu: What do the data say? (UNICEF, Suva, Fiji, 2014).

15 Mont, D. in Washington Group on Disability Statistics Blog Vol. 2020 (2019).

16 Mactaggart, I., Kuper, H., Murthy, G., Oye, J. & Polack, S. Measuring disability in population based surveys: the interrelationship between clinical impairments and reported functional limitations in Cameroon and India. PloS one 11, e0164470 (2016).

17 Samoa Bureau of Statistics, M. o. W., Community and Social Development, Pacific Community and UNICEF Pacific,. 2018 Samoa Disability Monograph: An Analysis of the 2016 Population and Housing Census. (UNICEF, Suva, Fiji, 2018).

18 Tonga Statistics Department. Disability in Tonga: Analysis of the situation of people with disability based on the 2016 Population and Housing Cernsus. (Kingdom of Tonga, 2019).

19 UNICEF Pacific & Kiribati National Statistics Office and Pacific Community. Kiribati Disability Monograph: From the 2015 Population and Housing Census. (UNICEF, Suva, Fiji, 2017).

20 UNICEF Pacific & Office of Planning & Statistics and Pacific Community. 2017 Palau Disability Report: An analysis of 2015 Census of Population, Housing and Agriculture. (UNICEF, Suva, Fiji, 2017).

21 Steptoe, A., Deaton, A. & Stone, A. A. Subjective wellbeing, health, and ageing. The Lancet 385, 640-648 (2015).

Report prepared by the International Centre for Evidence in Disability, London School of Hygiene & Tropical Medicine, with significant contributions and review by World Vision Vanuatu and the Vanuatu National Statistics Office.

Suggested Citation: International Centre for Evidence in Disability (ICED), Water, Women and Disability Study Report, London School of Hygiene & Tropical Medicine 2020 [Available from: https://www.lshtm.ac.uk/research/centres/international-centre-evidence-disability/research].