

Adapting menstrual health interventions for people with intellectual disabilities in emergencies

Jane Wilbur (the London School of Hygiene & Tropical Medicine) and Chloe Morrison (independent consultant)



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About the issue

Menstrual health is a public health issue, yet many women and girls in low- and middle-income countries still need to achieve it. People with disabilities are particularly disadvantaged and often excluded from interventions to improve menstrual health in development and humanitarian contexts. To start addressing this gap, the Bishesta campaign – a menstrual health intervention for people with intellectual disabilities and their caregivers was designed and delivered in Nepal’s development setting. The campaign was adapted for Vanuatu’s humanitarian emergencies and is called the Veivanua campaign. This *Frontiers of Sanitation* issue presents the study findings and explains the steps followed throughout these two processes. It includes recommendations to support others to adapt the campaigns for different settings.

Photo credits

Front cover: Campaign characters: Bishesta and Perana and Veivanua and Votahenavanua.

Credit: Jane Wilbur

This page: “Filling up my bag with calico.” **Credit:** ‘Failyln’

Next page: Large Bishesta doll. **Credit:** Jane Wilbur



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Introduction

The Bishesta campaign – a menstrual health intervention for people with intellectual disabilities and their caregivers in Nepal, was developed to help improve menstrual health for this population in non-humanitarian settings (Wilbur et al. 2021a). The campaign was developed by the London School of Hygiene & Tropical Medicine (LSHTM) and WaterAid and delivered in collaboration with the disability service provider, the Down Syndrome Society Nepal, and the Centre for Integrated Urban Development, a local WASH non-government organisation.

Following a positive feasibility study (Wilbur et al. 2019a), the Bishesta campaign was ready for efficacy testing or adapting for another context. Due to the lack of attention to people with disabilities' menstrual health during emergencies, World Vision and the LSHTM adapted the Bishesta campaign for humanitarian responses in Vanuatu and called it the Veivanua campaign.

This *Frontiers of Sanitation* issue presents: the research that preceded the development of these campaigns, the two campaigns, explains the adaptation process, and documents critical considerations for others wishing to revise the campaigns for different settings. This issue will interest practitioners working in menstrual health for people with and without disabilities in the development or humanitarian context.

Background

Menstrual health – a public health issue

Box 1: What is menstrual health?

Realising menstrual health means that all women, girls, and people who menstruate have accessible and appropriate information about the menstrual cycle and related hygiene practices. They have access to effective and affordable menstrual materials, water, sanitation, and hygiene (WASH) facilities where they can change, wash, and dispose of their menstrual materials hygienically and in private, wash their bodies and hands. They also have access to medical support for menstrual related disorders and discomforts. Importantly, it means an environment free from stigma and discrimination where people can make informed decisions throughout their menstrual cycle, and where they decide how to participate in life (Hennegan et al. 2021).

Menstrual health is essential for gender equality, sexual and reproductive health, educational attainment, employment, participation, and achieving sustainable development goals (Hennegan et al. 2019; Sommer et al. 2016 and 2021; Torondel et al. 2018; Das et al. 2015). However, many women and girls living in low-and middle-income countries have not achieved it. Menstrual stigma is pervasive and often internalised (Hennegan et al. 2019). In many settings, menstruation is considered 'dirty', 'impure' and 'contaminating'; it is not openly spoken about, which leads to misinformation, unhygienic practices and a reticence to seek support (ibid). Many women and girls who menstruate experience shame,

fear and anxiety (Garg et al. 2001; Irinoye et al. 2003; Sommer 2009; Mason et al. 2013). Challenges to menstrual health are often exacerbated during humanitarian emergencies as menstrual practices are often disrupted, causing further psychological stress (Sommer 2012).

Experiences of menstruation are not consistent. Menstrual health inequalities can be exacerbated when experienced by people who routinely face discrimination, which can further limit their access to services, resources and opportunities.

Menstrual health and disability

Box 2: Defining disability

A person with disabilities has a 'long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.' (OHCHR 2008).

Approximately one in six people globally have disabilities, and 80 per cent are invisible disabilities (e.g. visual impairment, hearing loss, cognitive impairments, autism, Asperger's syndrome and mental health conditions) (WHO 2022; The Disability Unit 2020).

Many people with disabilities face discrimination in multiple areas of life and face barriers to accessing education, healthcare and sexual and reproductive health, employment, and WASH services (Kuper et al. 2014; Mactaggart et al. 2018a and b; Kuper and Heydt 2019; Hameed et al. 2020). For instance:

- In Vanuatu, people with disabilities are statistically more likely to

face barriers to accessing WASH at home than their counterparts without disabilities (Mactaggart et al. 2021).

- Women and girls with disabilities face the same challenges in achieving menstrual health as people without disabilities, but they face additional ones because of disability discrimination (Wilbur et al. 2019b; 2021b).
- Many believe that people with disabilities do not have the same reproductive systems as non-disabled people, so they do not menstruate, are asexual and cannot and should not have children (WHO and World Bank 2011; Hameed et al. 2020)

Such misconceptions result in inadequate attention to people with disabilities' sexual and reproductive health and rights. A systematic review of interventions to promote sexual and reproductive health for people with disabilities could not identify any interventions that promoted family planning and contraception, maternal health, or safe abortion for people with disabilities (Hameed et al. 2020). Additionally, people with disabilities are even less likely than non-disabled women and girls to access menstrual health information (Wilbur et al. 2019b).

The joint monitoring programme reports that people with disabilities were 50 per cent less likely to participate in daily life when menstruating than non-disabled women and girls (WHO/UNICEF 2021). People with disabilities who rely on caregivers are often those with intellectual disabilities, and they face the most extreme consequences from inadequate menstrual health. Outcomes include physical restraint, verbal and physical violence, being put on long-term contraception, and sometimes sterilisation because of menstruation (Wilbur et al. 2019b and 2021c; Harvey et al. 2019). Reasons for these actions include that caregivers are not supported or guided to manage a person with intellectual disabilities' menstrual cycle, a dislike for menstrual care tasks, and fear of unwanted pregnancies. Furthermore, menstrual health information is often withheld from people with intellectual disabilities because it is

assumed that they would be unable to understand it, when efforts should be made to provide accessible and appropriate information that can be absorbed (Wilbur et al. 2019b, 2021b and c).

Progress has been made in tackling discriminatory legal frameworks, but implementing disability-inclusive WASH remains challenging (ODI 2018). Where policy and practice efforts are made, these tend to focus on physically accessible WASH services rather than providing relevant and accessible information, ensuring meaningful participation of people with disabilities, affordability, and supporting caregivers (Scherer et al. 2021; Wilbur 2022; Wilbur et al. 2022a, c).

The inclusion of people with disabilities in humanitarian responses

Humanitarian emergencies can exacerbate and cause disabilities because of trauma, injuries, inadequate medical care and disruption to other essential services (Handicap International 2015). People with disabilities are also more likely to die from disasters: data gathered after the Great East Japan Earthquake in 2011 found that mortality rates of people with disabilities were two to four times higher than those without disabilities (Japan Disability Forum 2013). Yet people with disabilities are often absent in humanitarian relief efforts (Robinson et al. 2020).

There is a growing recognition that menstrual health is a fundamental part of humanitarian responses, demonstrated by its inclusion in the Sphere Handbook and a toolkit for integrating menstrual health in emergencies (Sphere 2018; Sommer et al. 2017). Yet, people with disabilities, especially those with intellectual disabilities, are inadequately considered in delivering such efforts (Wilbur et al. 2022c and d). A recent review that mapped existing evidence on the inclusion of people with disabilities in menstrual health interventions delivered during emergencies found that this group faced additional barriers than women and girls without disabilities but that there was a dearth of interventions to address this (Wilbur et al. 2022c).



The Bishesta campaign

An evidence-based intervention

The Bishesta campaign was developed following the Behaviour Centred Design model (Aunger and Curtis 2016). It began with a systematic review of relevant literature conducted to explore menstrual health and disability and understand what, if any, menstrual health interventions exist that target this population (Wilbur et al. 2019b). Analyses of Nepal's WASH and menstrual health policies and guidance documents and their implementation in the Kavrepalanchok (Kavre) district were completed to assess the inclusion of disability compared to gender (Wilbur et al. 2021c). Findings revealed that menstrual health policy commitments for disability were largely absent. Professional understanding of the issues was low because there was no data or training on disability and menstrual health. Some efforts were made in schools, but these focused on improving physical access to WASH infrastructure. This missed the many children with disabilities who do not go to school. Furthermore, some caregivers sought to sterilise people with disabilities who could not independently manage menstruation.

Researcher: *“Have you ever been asked about sterilisation?”*

Participant: *“Yes. That is one of the questions the parents ask me. The caretaker and parents want disabled women to get surgical sterilisation, so there is no problem taking care of menstruation and no risk of unwanted pregnancy.”* (Service provider, Kathmandu)

A qualitative study investigated barriers to menstrual health experienced by women and girls with disabilities and their caregivers in the Kavre district (Wilbur et al. 2021b). Analyses of data showed that people with disabilities could be split into two groups - those who manage their menstruation independently but often with

difficulties and those who rely on caregivers for their menstrual health. This marks the biggest difference in implementing menstrual health interventions for people with and without disabilities. Interventions for the latter target the menstruator, whereas a person with disabilities might rely on a caregiver to achieve menstrual health. Therefore, caregivers need to be supported to appreciate the importance of and provide dignified menstrual care. However, caregivers received no information about how to provide menstrual care and felt particularly overwhelmed when the person was menstruating.

“She doesn’t understand, she won’t listen. [...] For someone like my daughter who does understand but wouldn’t remember, we can’t do much.” (Caregiver of a person with an intellectual disability)

Information on menstrual health was commonly withheld from people with intellectual disabilities, and few caregivers provided pain relief for menstrual discomfort. Many people with intellectual disabilities did not like wearing menstrual materials. Subsequently, some people leaked menstrual blood on their clothes and were abused by family members and the public.

The policy analysis and qualitative research showed that people with intellectual disabilities experienced the most negative outcomes from inadequate menstrual health. Few interventions existed globally for this group, so this population and their caregivers were targeted in the campaign.

Bishesta campaign target groups and behaviours

The Bishesta campaign was co-created with government officials, WASH, disability, and creative professionals working in Kathmandu and the Kavre district (Wilbur et al. 2018). Three target behaviours were identified for people with intellectual disabilities and caregivers. These behaviours addressed challenges highlighted in the systematic review and formative research. ‘Period packs’ were developed and contained several items that make the target behaviours attractive and easy to adopt. Table 1 presents the target group, behaviours, and period pack items distributed to trigger behaviour change.

Table 1: Bishesta campaign target groups, behaviours, and period pack items distributed to trigger behaviour change

TARGET GROUP	TARGET BEHAVIOUR	PERIOD PACK ITEM
YOUNG PERSON	Use a menstrual material	<ul style="list-style-type: none"> Storage bag containing a tailor-made cloth, menstrual pad and a strip of soft material for use at home Small bin
	Use pain relief	<ul style="list-style-type: none"> Pain bangle with three colours on it representing the severity of menstrual discomfort experienced
	Do not show menstrual blood in public	<ul style="list-style-type: none"> Shoulder bag to carry unused menstrual materials for use outside the home Two visual stories about Bishesta learning to manage menstruation as independently as possible with her caregiver’s support
CAREGIVER	Provide enough menstrual materials	<ul style="list-style-type: none"> Storage bag Shoulder bag Bin Menstrual calendar
	Provide pain relief	<ul style="list-style-type: none"> Pain bangle
	Show love and emotional support	<ul style="list-style-type: none"> Menstrual calendar Visual stories

Source: Author’s own

Figure 1 shows the contents of the period packs.

Figure 1.

Period pack contents: storage bag, shoulder bag, bin (left to right)



Source: Author's own

The Bishesta campaign is based on two fictitious characters, Bishesta (meaning ‘extraordinary’ in Nepali), who is a young Nepali with intellectual disabilities, and her caregiver, Perana (“motivation”), who motivates and supports Bishesta to achieve menstrual health (Figure 2). These characters have adopted the target behaviours so that Bishesta and Perana feel confident and comfortable when Bishesta is menstruating.

Figure 2.

Bishesta and Perana



Source: Raju Shakya (Sarab)

Campaign delivery

The Bishesta campaign was delivered by the Down Syndrome Society Nepal and the Centre for Integrated Urban Development members, with guidance from the LSHTM and WaterAid in the Kavre district. The intervention consisted of three group training sessions across ten people with intellectual disabilities (now referred to as ‘young people’ or ‘young person’) and their caregivers, who were a mix of family members and professionals. The training venue was decorated with blue and yellow campaign flags and a campaign banner depicting the target behaviours.

The facilitation team delivered the sessions as set out in a campaign manual (Wilbur 2019a). The information transferred in training was communicated visually and audibly through posters and role-play. Information was repeated regularly to reinforce learning.

A Bishesta doll (Figure 3), with removable clothes and underwear, was used with the young people to demonstrate how to place a menstrual material in underwear, how to change and dispose of used menstrual materials, and to introduce pain relief options (e.g. resting, massaging the stomach, drinking hot water, placing a hot water bottle on the stomach). The doll was also used to demonstrate the importance of caregivers showing understanding and kindness to young people who are menstruating. The doll had its own items from the period packs, so the young people practised using them with the doll before taking their period packs home. The young people were offered a small Bishesta doll with removable clothes, underwear, and menstrual materials to practice carrying out the target behaviours when they were not menstruating. A mirror with Bishesta and Perana on the border and a key ring was given to each young person to remind them of the target behaviours at home. Facilitators explained how to use the menstrual calendar with caregivers before distributing them.

Figure 3.
A large Bishesta doll



Source: Author's own

Visual stories depicting Bishesta and Perana carrying out the target behaviours mirrored exercises in the training. These stories were introduced to participants in the training sessions before they were distributed. Figure 4 shows a snapshot of a visual story.

Figure 4.
Section of 'I change my pad' visual story



Source: Raju Shakya (Sarab)

Wilbur et al. (2021a) provides more information on the campaign and its delivery. The Bishesta campaign is free to download (see Wilbur 2019b).

Evaluation of the Bishesta campaign¹

An evaluation of the Bishesta campaign found that the intervention was feasible and acceptable for young people, caregivers, and facilitators (Wilbur et al. 2019a). Improvements were recorded across all target behaviours, and there were indications that young people felt more confident and comfortable when menstruating than before the intervention.

“She learnt many things; she knows where to keep her pads. When I tell her to change her pads and clothes, she does them by herself and also washes them. She didn't use menstrual products before, but after the three training, there have been good changes in her behaviour.” (Caregiver)

Most of the items from the period packs were used, but the pain bangle and the menstrual calendar were too complicated for participants to understand. In conclusion, the Bishesta campaign worked within the small sample size but needed efficacy testing before scaling up. Alternatively, it could be adapted to a different setting by following a similar process as in Nepal.

¹ Further details on the evaluation, including the research design, methods and activities are published in Wilbur et al. (2019a)



Adapting the Bishesta campaign for Vanuatu's humanitarian response

Menstrual health in Vanuatu's humanitarian responses

Vanuatu is a collection of 83 islands in the Pacific region. It is the world's most 'at risk' country for natural hazards as it is highly vulnerable to cyclones, earthquakes, flooding, and volcanic eruptions (Statista 2021; ReliefWeb 2021). Tropical Cyclone Harold hit the country in 2020 during COVID-19, which affected more than 159,000 people (ReliefWeb 2021; DFAT nd.). Humanitarian response efforts, coordinated by the government's National Disaster Management Office, included promoting menstrual health and distributing hygiene kits, including reusable menstrual materials.

With funding from Elrha's Humanitarian Innovation Fund, World Vision and the LSHTM adapted the Bishesta campaign for the humanitarian setting in Vanuatu and assessed its feasibility.

This initiative followed the completion of a mixed-method population-based disability survey that explored the menstrual health experiences of people with and without disabilities in TORBA and SANMA provinces in Vanuatu (Mactaggart et al. 2021; Wilbur et al. 2021d). Study findings fed into developing the Laetem Dak Kona (LDK) project, an inclusive WASH programme targeting people with disabilities in the two provinces. Improving menstrual health for people with disabilities is a core component of the LDK project and, therefore, of strategic importance to World Vision Vanuatu.

Building an evidence base

Like in Nepal, the process began with a review of existing evidence to explore the inclusion of disability in global menstrual health humanitarian responses compared to efforts for women and girls without disabilities (Wilbur et al. 2022c). Results highlighted limited

participation of people with disabilities in menstrual health efforts, reduced access to WASH services and social support networks, inaccessible distribution points for cash transfers and hygiene kits and few outreach programmes. Efforts that did exist focused on the provision of physically accessible WASH services. Caregivers, some of whom were providing menstrual care for the first time, were not given any guidance about how to carry out the role. The review established a significant gap in evidence and menstrual health interventions for women and girls with disabilities in humanitarian settings.

Context-specific evidence was generated through a qualitative study to explore the menstrual health experiences of women and girls with intellectual disabilities and their caregivers during humanitarian crises in Vanuatu (Wilbur et al. 2022d). The study was conducted in the SANMA province (northern Vanuatu), where most people had been affected by emergencies, including Tropical Cyclone Harold, which made landfall in the province.

Young people with intellectual disabilities, their caregivers, government officials, disability service providers, and humanitarian response agencies were interviewed. As the young people enjoyed interacting with the Bishesta doll in Nepal, a doll resembling a ni-Vanuatu young woman was used for the first time to explore and observe young people's menstrual behaviours (e.g. disposal of menstrual materials) during data collection. The doll proved to be an effective way to capture the attention of young people and observe very private behaviours. Researchers recorded the reaction of some young people to the doll during their interactions in their field notes:

"When I brought out the doll, she smiled widely, and her eyes brightened. The doll really got her attention." (Researcher's field notes)

Study findings highlighted that caregivers are primarily concerned with maintaining the young person's safety and privacy during humanitarian emergencies. However, most places that families evacuated to during Tropical Cyclone Harold did not allow this. Consequently, many families either stayed in their destroyed homes or returned to their homes to bathe behind trees that were still standing instead of staying at evacuation centres. Both men and women assisted the young person with menstrual health, thus challenging gendered assumptions. Caregivers reported that some young people's support requirements increased after the crisis, which meant caregivers did not have time to dedicate to livelihood opportunities, so could not earn the income needed to rebuild their homes and recover from the emergency. Caregivers were thankful for the menstrual materials distributed in the hygiene kits, mainly because they were unaffordable. However, they requested more reusable menstrual materials because heavy rains follow cyclones, which makes it difficult to dry materials.

"...with the rain, it is not enough. When it rains, six is not enough. I'd wash these ones, but the others would not be dry yet." (Caregiver)

Caregivers also asked for a greater choice of menstrual materials to suit the young person's requirements. For instance, adult-sized diapers were helpful for people who also experience incontinence, which often worsened because of the trauma caused by the emergency.

Key informants noted the importance of promoting menstrual health for people with intellectual disabilities and their caregivers in all menstrual health interventions before, during, and after emergencies. Key informants said that could ensure that people with disabilities are not excluded from humanitarian responses.

"If we have that specific initiative available [for people with disabilities] during peacetime, we are working with them, we understand them, we are creating a relationship. [...] Because when it comes to disaster, and we are making quick decisions, it's very easy to overlook the need of persons with disabilities." (Key informant)

Key informants also highlighted that mainstreaming disability within all menstrual health interventions could increase the target group's knowledge, and understanding exist about the importance of menstrual health before hygiene kits are distributed. Key informants thought this could lead to greater acceptance of and use of menstrual materials.

Creating the Veivanua campaign

Evidence from the literature review and qualitative study results were analysed to assess if the target groups and behaviours in the Bishesta campaign were appropriate for Vanuatu's humanitarian responses. The target groups were relevant, as were most of the target behaviours. The only revised behaviour was 'don't show blood in public', which changed to 'don't show used menstrual materials in public'. This shift recognises that people may leak menstrual blood on their clothes for various reasons, including ineffective or inappropriate menstrual materials, not changing materials often enough, or, as in the case of young people in Nepal, an aversion to wearing menstrual materials. The latter has been noted in evidence from Taiwan, India, and England (Chou and Lu 2012; Thapa and Sivakami 2017; Mason and Cunningham 2007), though this was not widely reported in our Vanuatu study. The new target behaviour, 'don't show used menstrual materials in public', more explicitly connects to changing menstrual materials in private.

The Bishesta campaign was adapted in the following ways for the new context:

1. The campaign materials underwent a comprehensive adaptation process to ensure they were suitable for both the Pacific and humanitarian context and revised target behaviour.
2. After the campaign, a pilot was also conducted to test the suitability of period underwear with participants as an alternate menstrual material for future humanitarian responses (see Box 3).
3. In Nepal, a shoulder bag was used for young people to take menstrual materials with them when they left home. In Vanuatu, a small drawstring bag with waterproof lining was used instead to account for some young people's physical disabilities, which would make opening the shoulder bag difficult. A waterproof lining was included so reusable menstrual materials that needed washing could be hygienically stored in public. Figure 5 shows the contents of the Veivanua campaign period packs.

Figure 5.

Contents from the Veivanua campaign period packs (top row): large menstrual storage bag, menstrual bin; (bottom row): reusable menstrual materials, small drawstring bag.



Source: Author's own

- The Bishesta campaign menstrual calendar, which was difficult for caregivers to understand, was simplified (Figure 6).

Figure 6.
Bishesta campaign and Veivanua campaign menstrual calendars (left to right)



Source: Author's own

- Based on the Nepal feasibility study, items such as the mirror, key ring, and campaign banner were removed due to cost. A pain bangle was not produced because it was too difficult for the participants to understand in Nepal.
- Some of the most significant adaptations were regarding the visual story and campaign images. In Nepal, the Bishesta campaign included two visual stories: I Change My Pad and I Manage. In Vanuatu, critical elements of both stories were combined to make one visual story titled I Manage. This revision recognised that one book would be easier to distribute in an emergency, keep at home and in storage with World Vision Vanuatu and Vanuatu Society for People with Disabilities for use in future disasters. The revision also reduced printing costs.

- Visual images were adapted to depict a humanitarian context in the Pacific, with many pictures informed by the formative research findings. Images included the family preparing for an emergency, including taking menstrual materials and evacuating to safety (Figure 7).

Figure 7.
Section of the 'I Manage' visual story



Source: Arlene Bax

1. The Veivanua campaign visuals also aimed to subtly challenge gender norms and menstrual taboos by including men as caregivers and supporting menstrual health.
2. In Nepal, the young person was depicted as a young woman with Down syndrome. In Vanuatu, very few participants in the formative research had Down syndrome, so the visual representation of the Veivanua character was changed.

3. The doll was also adapted to reflect a young person in Vanuatu (Figure 8). The doll was produced in collaboration with a local women-led social enterprise connected to a local school that works with children with disabilities. Working through a local social enterprise to produce the dolls ensures that ongoing production is not dependent on the global supply chain. The doll was tested with some of the students with disabilities for appropriateness. The doll was further refined based on experience using it in the formative research, including reducing the size of the doll and its facial features.

4. Lastly, the campaign colours were changed from blue and yellow in Nepal to yellow and purple to further differentiate the two campaigns.

Figure 8.
The Veivanua doll



Source: Author's own

Box 3: Piloting period underwear

Throughout the campaign, project staff and caregivers highlighted that reusable menstrual materials distributed in the Veivanua campaign such as reusable pads which often have press studs, could be challenging to use, especially if the caregiver or young person has a physical or visual impairment.

In response to this feedback, World Vision partnered with [Reemi](#), a New Zealand-based social enterprise, to pilot and test the suitability of period underwear with participants as an alternative, environmentally sustainable menstrual material for future humanitarian responses.

All participants who received the period underwear said they preferred them to other menstrual materials, such as disposable or reusable pads. Young people found them easier to change independently. Participants also reported that the period underwear were more comfortable and absorbent than other materials.

The period pants could be washed and dried discretely because they look like standard underwear. Some caregivers reported the period underwear was easier to wash without touching menstrual blood. While caregivers did not report a lack of water for washing as a challenge, in times of low rainfall or drought, period underwear may not be suitable.

The period underwear was not piloted as part of the research study because the delivery date was delayed, and it took extra time to distribute the correct sizes.

Campaign delivery

In Vanuatu, the campaign reached 38 young people and their caregivers across four islands in the SANMA Province. Young people had been impacted by tropical cyclone Harold and, in some instances, had also relocated to SANMA Province as part of the Ambae volcano evacuation in 2017 and 2018 (Rovins et al. 2020).

The campaign was delivered in Vanuatu from May to August 2022, with most participants having a two or three-week gap between training sessions. While this was a shorter timeframe than in Nepal, it demonstrates that delivering the campaign within short humanitarian grants is possible, which often ranges from three to six months. In Vanuatu, the facilitation team consisted of staff from World Vision, a young person with disabilities and a caregiver. Staff from the Vanuatu Society for People with Disabilities were members of the formative and feasibility study research teams.

In Vanuatu, the campaign was initially planned to be delivered in group and household settings. Group training was designed for young people who lived in nearby communities, and household training was planned for participants who lived in more remote areas or had higher dependencies on their caregivers. After reflecting on the first group training (consisting of five participants and their caregivers), it was decided that household visits would be more appropriate and effective, even though it would take longer to reach all participants. The group training was anticipated to provide a peer network for caregivers and a social activity for young people; however, some unintentional consequences of the approach were observed. Lead facilitators noted that some caregivers were shy or hesitant to engage in group discussions. These observations were confirmed in interviews with caregivers during the feasibility study. Furthermore, the group setting proved overwhelming and distracting for young people with limited or no previous experience in a social setting with peers or groups outside the home.

The household visits provided a safe environment for caregivers to ask questions while the young person was comfortable in a familiar setting. As the campaign was delivered in the immediate aftermath of Vanuatu's first case of COVID-19 community transmission, the household setting also provided a more COVID-19-safe environment. While household training had significant benefits, the approach came with some challenges. Many families moved in the aftermath of disasters or to seek employment, so they were not readily available for training sessions. Consequently, some households had much longer gaps between training sessions than other families. In some instances, the primary caregiver changed (primarily due to moving for employment opportunities), so the training was repeated where possible with the new caregiver.

COVID-19 restrictions delayed the delivery start date of the campaign, but implementation was not significantly impacted. However, due to strict Vanuatu international border closures (borders only opened to non-residents in July 2022), facilitator and research team training was delivered by the LSHTM using a hybrid approach of pre-recorded PowerPoints, in-person facilitation delivered by the in-country research coordinator, and daily debriefs with the LSHTM.

Evaluation of the Veivanua campaign²

An evaluation of the Veivanua campaign was conducted 2-4 weeks after the completion of training. The study participants were 30 young people and 35 caregivers (31 females, 4 males). Results show that the campaign is feasible and acceptable for Vanuatu's emergency context.

Caregivers noted new and increased knowledge about menstrual health and how to support young people's menstrual health before, during, and after emergencies. Caregivers said they would use the menstrual bin and large storage bag to transport contents during the next emergency. Young people's ability to manage menstruation

² More details on the feasibility study research design and findings will be published in a forthcoming article by Wilbur et al.

more independently increased. After training sessions, young people practised changing and disposing of the small doll's menstrual materials and telling others that the doll was menstruating, thus indicating greater knowledge of and communication about menstrual health. Young people and caregivers regularly looked at the visual story, using it to reinforce learning gained during training sessions.

All the contents of the period packs were used. Caregivers appreciated the reusable menstrual materials but requested more to ensure they had enough for the young person to wear, wash and dry during post-cyclone rains.

However, findings related to the menstrual calendar were mixed: some caregivers used it and found it helpful for tracking the young person's menstrual cycle, but some could not understand how to use it.

Calendars are widely used to support tracking the menstrual cycle in menstrual health interventions, with apps gaining popularity where people can access the internet (Broad et al. 2022; Karasneh et al. 2020; Schantz et al. 2021; Montgomery et al. 2012; Oster and Thonton 2011). Such methods support people to know when they will menstruate and better understand the premenstrual syndrome and any changes in the menstrual cycle (Worsfold 2021). Yet, an unintended consequence of using the menstrual calendar in the Veivanua campaign was that some caregivers reported using it to track when the young person's fertility and keeping them at home at this time to guard against unwanted pregnancies because of sexual violence. During the formative research, caregivers highlighted that experience and fear of the latter led them to keep the young people at home or accompany them when outside (Wilbur et al. 2022d).

Going forward, the Veivanua campaign training session on the menstrual calendar will be revised to enhance caregivers' understanding that it should be used to track the young person's menstrual cycle, to remind caregivers to fill the menstrual storage bag and remind the young person about how to manage menstruation.

Facilitating the 'direct voice' of people with intellectual disabilities can be challenging. Often, data collection methods rely on proxy interviews with caregivers who report on behalf of the young person. In this study, young people were supported to express themselves visually through photovoice, a visual research methodology (Bhakta 2020). This is the first time this research method has been used with people with intellectual disabilities to explore their menstrual health, and the results were beautiful. Figure 9 presents a selection of self-directed portraits. The photo captions are generated from the interview transcripts with the young person. The images demonstrate a sense of ownership over the contents of the period packs and an understanding of their purpose and use by the two participants.

Figure 9.
Selection of self-directed portraits taken during Photovoice



"Dolly and book." Credit: 'Josephine'



"Filling up my bag with calico." Credit: 'Failyln'

How to incorporate the Veivanua campaign into disaster preparedness plans

The Veivanua campaign could be incorporated into Vanuatu's disaster preparedness plans. Figure 10 depicts how.

Figure 10.

How to incorporate the Veivanua campaign in different stages of Vanuatu's disaster preparedness plans



- Pre-position period packs and campaign materials.
 - Raise awareness of humanitarian actors and organisations of persons with disabilities (OPDs) about the importance of menstrual health response for people with intellectual disabilities in emergencies.
 - Train actors to deliver the campaign.
 - Deliver the campaign.
- Distribute period pants and campaign materials. Include visual instructions about how to use menstrual materials.
- Deliver the campaign.
 - Repeat awareness and training activities from Preparedness phase.

Things to consider in each stage:

Preparedness: Do a desk review to understand the humanitarian context, including gaps in providing shelter, WASH, and cash transfers in crises in your context, as well as staff's understanding of intellectual disability and menstrual health. Findings would inform awareness-raising activities. Delivering menstrual health training before a disaster would support people with intellectual disabilities and their caregivers to be better prepared and understand how to use menstrual materials distributed during the immediate response phase.

Immediate response (0-3 months after a disaster): People with disabilities may require more menstrual and incontinence materials, especially after a disaster. People with intellectual disabilities and their caregivers may be unable to reach distribution points or evacuation centres. Provide outreach to ensure period packs and campaign materials reach people.

Medium long-term recovery (3-12 months): People may be highly transient and move throughout the recovery period, making it difficult to conduct the Veivanua campaign's second training session. Consider conducting campaign training sessions on consecutive days. If people are displaced or living in temporary shelters, collaborate with others to improve access to WASH services for washing reusable menstrual materials and changing in private. If distributing disposable menstrual products, consider safe disposal and/or a reusable option if appropriate.



Key stages for adapting the Bishesta and Veivanua campaigns for other settings

- 1. Obtain ethical approval before data collection to protect research participants and researchers.** This is vital because the campaigns target people who may be vulnerable. The ethical approval process will help you consider and manage the risk of harm. Conduct research that adheres to ethical standards.
- 2. Form a transdisciplinary team including researchers, practitioners and people with lived experience of disability.** Ensure people with disabilities, Organisations of Persons with Disabilities, or disability service providers are involved at every stage of the adaptation process, including formative research, design and delivery, and evaluation.
- 3. Identify young people and caregivers for formative research, the campaign delivery, and the feasibility study.** Use the Washington Group Short Set of questions to identify people with intellectual disabilities (those who have 'a lot of difficulty' or more remembering or concentrating) (Washington Group on Disability Statistics 2010). Ask further questions, such as if the young person is menstruating and if they require support to manage menstruation. Caregivers of identified young people should be invited to participate. It should be clear through all stages that people's participation is voluntary.
- 4. Conduct formative research to understand current menstrual behaviours in the new setting.** Consider using participatory approaches, such as using a doll in interviews, photovoice, accessibility and safety audits of WASH facilities used for menstrual health, cue cards, and talking mats (WEDC, LSHTM and WaterAid n.d.; Wilbur 2019c; Lewis et al. 2008; Murphy et al. 2007). Data collection tools like motive mapping, personal histories, and touchpoints can be adapted for menstrual health. If target behaviours are relevant, move to the next step. If not, the campaign will need redesigning, including identifying the target behaviours and triggers to change these.

5. **Adapt the campaign for the new context.** This should include the following:

- Updating visuals to suit the socio-cultural context. Adapt campaign characters, the community setting, menstrual materials, and disaster type. Show both men and women supporting the menstrual health of the person with intellectual disabilities, and depict people with disabilities in communities in the visuals. Test visuals with the target population to ensure relevance.
- Ensure consistency throughout different campaign materials. Choose campaign colours for the character's clothes, the visual story, and the menstrual bags. The visual story should depict the same menstrual materials distributed throughout the campaign.
- The doll should look the same as the character with disabilities in the visual story. The hairstyle, dress, and accessories should match. This consistency helps young people link messages from the visual story to the doll and themselves.

6. **Before delivering the campaign, pilot training sessions with young people and their caregivers to ensure they are appropriate. Ensure materials are revised to address participant feedback.**

7. **Identify if household or group setting training would be most suitable for the context or trial a combination of both.** If using a group setting, test the ratio of facilitator to participants and the group size to ensure they are appropriate for the young people.

8. **Monitor the delivery.** If delivery is not working well, adapt the approach during implementation; monitor that and change it again if required.

9. **Conduct a feasibility study to evaluate the campaign.** Use participatory tools such as the doll and photovoice to include the perceptions of young people with intellectual disabilities.

And finally...

The Bishesta and Veivanua campaign are important contributions to beginning to meet the menstrual health requirements of people with intellectual disabilities and their caregivers. However, an impact evaluation is required to understand if the two campaigns can lead to sustained behaviour change.

In terms of future delivery, the campaigns should be delivered through the 'twin-track' approach (Wertlieb 2019). This would combine the implementation of the Bishesta or the Veivanua campaigns alongside mainstreaming disability inclusion in all other menstrual health interventions. The twin-track approach for menstrual health is set out in Figure 11. Central to the twin-track approach is ensuring the full and meaningful participation of people with disabilities in planning, designing, implementing, monitoring, and evaluating interventions.

Figure 11.
The twin-track approach for disability-inclusive menstrual health interventions



Applying the twin-track approach to menstrual health could reduce inequalities and improve health outcomes for a population often excluded from vital public health interventions.

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Adapting menstrual health interventions for people with intellectual disabilities in emergencies

Menstrual health is a public health issue, yet many women and girls in low- and middle-income countries still need to achieve it. People with disabilities are particularly disadvantaged and often excluded from interventions to improve menstrual health in development and humanitarian contexts. To start addressing this gap, the Bishesta campaign – a menstrual health intervention for people with intellectual disabilities and their caregivers was designed and delivered in Nepal’s development setting. The campaign was adapted for Vanuatu’s humanitarian emergencies and is called the Veivanua campaign. This issue of *Frontiers of Sanitation* presents the study findings and explains the steps followed throughout these two processes. It includes recommendations to support others to adapt the campaigns for different settings.

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