

FRONTIERS of SANITATION

Innovations & Insights

Issue 16, October 2020

the
sanitation
learning
hub

Incontinence: We Need to Talk About Leaks

Claire Rosato-Scott (University of Leeds); Dr Dani J. Barrington (The University of Western Australia); Dr Amita Bhakta (Independent Consultant); Dr Sarah J. House (Independent Consultant); Dr Islay Mactaggart and Jane Wilbur (London School of Hygiene & Tropical Medicine)



About The Sanitation Learning Hub

For over ten years, IDS's Sanitation Learning Hub (SLH, previously the CLTS Knowledge Hub) has been supporting learning and sharing across the international sanitation and hygiene (S&H) sector. The SLH uses innovative participatory approaches to engage with both practitioners, policy-makers and the communities they wish to serve.

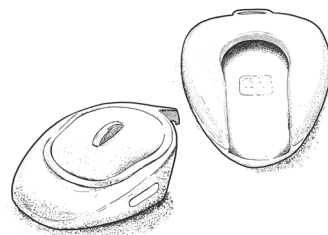
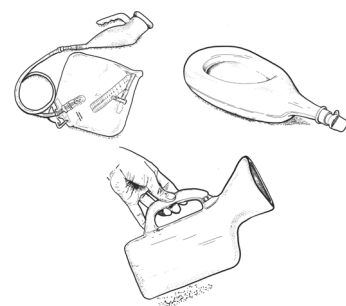
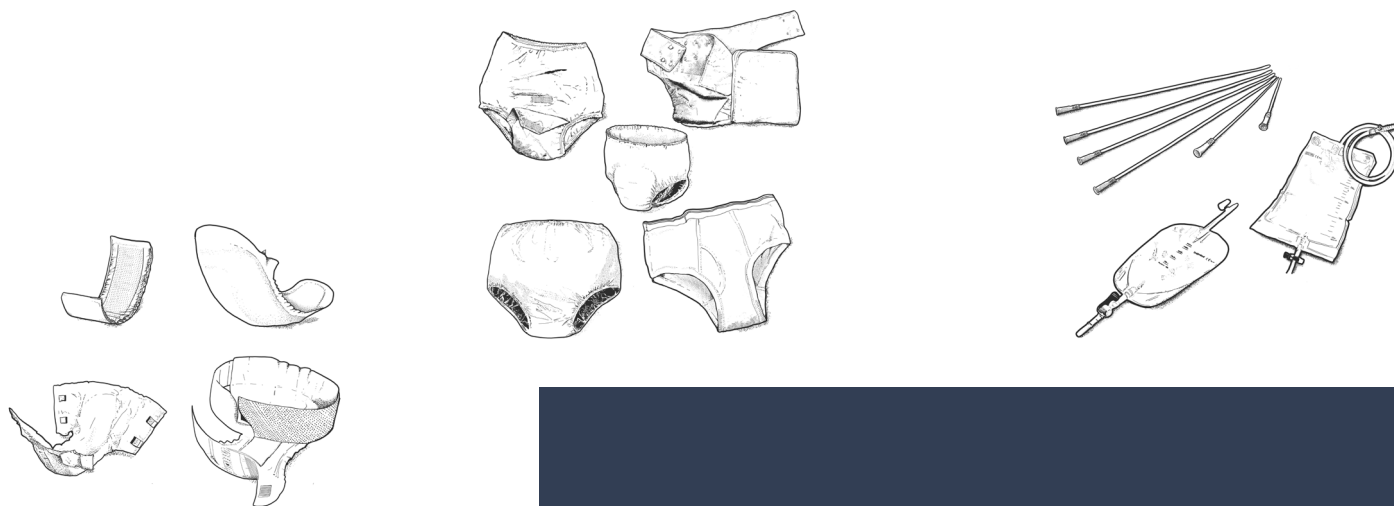
We believe that achieving safely managed sanitation and hygiene for all by 2030 requires timely, relevant and actionable learning. The speed of implementation and change needed means that rapidly learning about what is needed, what works and what does not, filling gaps in knowledge, and finding answers that provide practical ideas for policy and practice, can have exceptionally widespread impact.

Our mission is to enable the S&H sector to innovate, adapt and collaborate in a rapidly evolving landscape, feeding learning into policies and practice. Our vision is that everyone is able to realise their right to safely managed sanitation and hygiene, making sure no one is left behind in the drive to end open defecation for good.

Front cover and inside cover images

Front cover: *"I can't sit with them. I have some friends but most of them left me and made me feel even more lonely and sad. I feel upset seeing them move around and sit together laughing and smoking. I sit and cry but then I don't want people to see me cry so I try and hold my tears back. They go off to the city, especially Thar, where we used to work and they harvest. You know, it is harvest season? We used to have so much fun in harvest season and now I can't even work."* (Ansari 2017). *Credit:* PhotoVoice photo by Poonmo, who has a disability and experiences incontinence

Page 1: Eating, bathing and toileting in the same room is unhygienic. *Credit:* PhotoVoice photo by Edeline, who has a disability and experiences incontinence. ICED (2020)



Incontinence: We Need to Talk About Leaks

Claire Rosato-Scott (University of Leeds); Dr Dani J. Barrington (The University of Western Australia); Dr Amita Bhakta (Independent Consultant); Dr Sarah J. House (Independent Consultant); Dr Islay Mactaggart (London School of Hygiene & Tropical Medicine) and Jane Wilbur (London School of Hygiene & Tropical Medicine)

Correct citation: Rosato-Scott, C., Barrington, D.J., Bhakta, A., House, S.J., Mactaggart, I. and Wilbur, J. (2020) 'Incontinence: We Need to Talk About Leaks', *Frontiers of Sanitation: Innovations and Insights* 16, Brighton: IDS, DOI: [10.19088/SLH.2020.005](https://doi.org/10.19088/SLH.2020.005)

First published in 2020

© Institute of Development Studies 2020

Some rights reserved – see copyright license for details.

ISBN 978-1-78118-696-1

For further information please contact:

The Sanitation Learning Hub, Institute of Development Studies, University of Sussex, Brighton, BN1 9RE

Tel: +44 (0)1273 606261

Email: SLH@ids.ac.uk

Web: <https://sanitationlearninghub.org/>

This series is licensed under the Creative Commons Attribution-Non-Commercial-NoDerivs 3.0 Unported License (<http://creativecommons.org/licenses/by-nc-nd/3.0/>).

Attribution: You must attribute the work in the manner specified by the author or licensor.

Non-commercial: You may not use this work for commercial purposes

No Derivative Works: You may not alter, transfer, or build on this work.

Users are welcome to copy, distribute, display, translate or perform this work without written permission. For any reuse or distribution, you must make clear to others the licence terms of this work. If you use the work, we ask that you reference the SLH website (<https://sanitationlearninghub.org/>) and send a copy of the work or a link to its use online to the following address: The Sanitation Learning Hub, Institute of Development Studies, University of Sussex, Brighton, BN1 9RE, UK (SLH@ids.ac.uk).

Consent has been given to take and use all of the photos in this publication.

This document has been financed by the Swedish International Development Cooperation Agency, Sida. Sida does not necessarily share the views expressed in this material. Responsibility for its contents rests entirely with the author.



Acknowledgements

The authors would like to thank everyone who courageously shared their experiences of living with incontinence which will help others learn how to work with and better support people living with incontinence.

Thanks also to Sian White (LSHTM) and Robert Chambers (IDS) for peer reviewing the publication and providing valuable comments and suggestions. The authors would also like to thank the informal email group of professionals interested in incontinence in low- and middle-income countries (LMICs), whose knowledge and experience this issue is primarily based on. For more information about the group, and the tools and resources that they have collated, please refer to <https://wash.leeds.ac.uk/incontinence-and-wash/>.

Key documents include:

- ✚ Rosato-Scott, C., Giles-Hansen, C., House, S., Wilbur, J., Macaulay, M., Barrington, D.J., Culmer, P., Bhakta, A.N and Burke, L. (2019):
 - ◆ *Guidance on supporting people with incontinence in humanitarian and low- and middle-income contexts (LMICs)*, LMIC-Incontinence-email-group. DOI: <https://doi.org/10.5518/100/13>
 - ◆ *Summary guidance: Supporting people with incontinence in humanitarian and low- and middle-income contexts (LMICs)*, LMIC-Incontinence-email-group. DOI: <https://doi.org/10.5518/100/14>
 - ◆ *Case studies on supporting people with incontinence in humanitarian and low- and middle-income contexts (LMICs)*, LMIC-Incontinence-email-group. DOI: <https://doi.org/10.5518/100/15>
 - ◆ *References on supporting people with incontinence in humanitarian and low- and middle-income contexts (LMICs)*. LMIC-Incontinence-email-group
- A [checklist](#) accompanies this publication, which can be used to increase your understanding of incontinence and the options available to support people living with the condition; and provide guidance on how to talk about incontinence.

Anyone, of any gender, at any age, can leak urine or faeces.

What would you do if it happened to you?

Imagine if you'd woken up this morning and you'd wet the bed. What would you do? Have a wash, put on clean clothes, change the bedding and put it in a washing machine? You may go to the shop and buy an incontinence pad. And perhaps if you knew that there was help available for leaking urine you'd make an appointment to see a doctor next week and then just carry on with the rest of your day, dignity intact.

Now imagine if you'd woken up this morning and you'd wet the bed. But to have a wash, or clean your clothes and bedding, you'd have to walk for an hour to collect water. Imagine you are frightened to walk there alone, the path is steep and you struggle to use the hand pump. Even if you did get water, you don't have enough soap so the smells would linger anyway. And after all that effort, you have nothing to wear to soak up urine if it happens again. What if you didn't know that leaking urine was common, and you spent the rest of the day worried about your health and too embarrassed to go to work in case people could tell? What if you were worried that your partner would hit you again for making a mess so you had very little to drink all day for fear of it happening again?

What can you do to support people living with incontinence?

To start, we need to talk about leaks.



Credit: Sanitation Learning Hub/ Sandra Stauffer (all illustrations in this publication are original)



Introduction

Incontinence – the involuntary loss of urine or faeces – is a global health, protection and social care challenge that has a significant impact on the quality of life of people that experience the condition, and those who care for people that do.

In higher-income countries with well-developed healthcare systems and high levels of access to sanitation and hygiene facilities, experience shows that simple behavioural changes and technologies can bring dramatic improvements to the quality of life of those who endure the condition daily (Dumoulin *et al.* 2014). It is hoped that adapting such methods for managing incontinence to low- and middle-income countries (LMICs) will also benefit residents that experience the condition, or who care for people that do (Rosato-Scott and Barrington 2018).

In many LMICs, knowledge of incontinence is rare, understanding of the condition is still in its early stages (including definitions, prevalence, people's perceptions and experiences of incontinence, and the best ways to manage it), those who experience it are stigmatised, and the provision of support is lacking. If the global community is to achieve the Sustainable Development Goals, particularly those relating to ensuring access to universal water, sanitation and hygiene for all (Goal 6) and ensuring health and well-being for all (Goal 3), there is a need to better understand incontinence in LMICs, and how best to support people living with the condition to improve their quality of life.

The first step to achieving greater understanding and providing better support is to talk to people that are living with incontinence, or who know people that are, to understand their daily experiences of living with the condition. But the stigma associated with the condition can prevent people with incontinence from speaking openly about the challenges that they are facing and they may even resort to isolating themselves from their family, friends and wider community. Therefore identifying people who may need support poses some challenges.

This issue of *Frontiers of Sanitation* aims to provide the water, sanitation and hygiene (WASH) sector with:

- A basic introduction to incontinence and the realities that people living with incontinence face;
- Practical suggestions for how to identify and engage with people living with incontinence to start 'talking about leaks'; and

- Practical suggestions for the WASH sector (and others) to contribute to reducing inequalities associated with incontinence.

This issue primarily draws on the knowledge and experience of an informal group of international professionals interested in incontinence in both humanitarian and development contexts in LMICs, which the authors have represented to the best of their ability. The issue relies heavily on emergent research and a relatively small number of case studies on incontinence in LMICs that have been collected to date, and it is hoped that this resource will act as an advocacy tool to push the WASH sector to do more learning and research on this topic. To assist with this, a list of learning and research priorities has been provided ([p39](#)), along with an accompanying [checklist](#) on how to talk about incontinence.

Box 1: Why has so little been done by the WASH sector to understand incontinence in LMICs?

- There is so much stigma associated with incontinence that the condition is rarely spoken about, even by medical professionals, and people that experience incontinence – including people with disabilities – are often hidden from view (either by personal choice or by families/communities);
- Incontinence is not well-known as an issue and rarely features on WASH agendas including at the international level;
- Getting incontinence onto WASH agendas is further hindered because it is a symptom, not a disease; whilst it can be life-threatening, it does not affect as many people as many communicable diseases; it is a cross-sectoral issue, which can present challenges for who should 'take responsibility'; and it isn't a 'glamorous' issue.

Cross-sectoral support for people living with incontinence, or supporting those that do

Support for people with incontinence cuts across a number of sectors including: health (including nutrition and occupational therapists); protection; gender-based violence; disability and older persons; midwifery; children; gender; livelihoods and WASH. WASH professionals should not underestimate the role they have to play as members of this support team.

In order to provide appropriate and effective support to people with incontinence, it is very important for specialists from all sectors to speak to people living with incontinence or who care for those that do to understand their experiences and needs, and to coordinate and work together. Support strategies can include education about diet (including the reduction of aggravating agents such as caffeine), fluid intake (both volume and timing), a regular toilet routine, pelvic floor exercises and toilet posture (especially for children). It is also particularly critical that people who face mobility challenges and also live with incontinence gain support from health or disability professionals, as for example, bed sores can lead to severe health consequences or even death.

One of the challenges that can be faced is that not all sectors may have professionals with expertise in incontinence. For example, within the WASH sector it may be difficult to a) know who to approach for support, and b) to gain training and awareness to help people with incontinence more effectively as part of WASH programmes.

Box 2: Good practice in Bhutan

A national study led by the Public Health Engineering Division of the Ministry of Health and SNV, aimed to identify who were the final 5-10 per cent of the households in Bhutan left to build and use an improved latrine. The study included consideration of how to work more effectively across sectors to better support people living with incontinence, and one health assistant was very active in ensuring such cross-sectoral support whilst also undertaking advocacy and education on behalf of people with incontinence and providing advice.

“When there are incontinence issues, they [the health assistants] refer the person to the nearest Basic Health Unit (BHU), or sometimes they advise to keep the urine and shit pan ready near by the patient. Patients who are bed ridden are using adult diapers. The Health Assistant advocates and advises how to manage incontinence issues after people have been screened to leave the BHU. He also educates about causes of incontinence issues. He suggested that the [National Rural Sanitation and Hygiene Programme in Bhutan] programme could include incontinence issues, such as teaching people how to use and make containers, and the importance of visiting BHUs and getting health services when people have incontinence issues”.
(Health Assistant, Bhutan, in Choden and House 2019)

What is incontinence?

Incontinence is the medical term to describe the involuntary loss of urine or faeces. It can also be described as leakage of urine or faeces; where a person is not able to control when they urinate or defecate; or where a person is not able to hold on to their urine or faeces. In some languages there may not be an equivalent word for incontinence. Conversely, when a person is continent they are able to control their bladder and bowel movements.

The level and severity of incontinence experienced varies between people, and for each person can also vary day to day and over time. A person with incontinence can experience leakage occasionally, regularly or constantly, and leakage can happen at any time, day or night.

Types of faecal (or bowel) incontinence (Guy’s and St Thomas’ 2014):

- *Urge*: when an individual is aware that bowels need to be opened to pass faeces, but there is such an urgency that a toilet cannot be reached in time;
- *Passive*: when an individual is not aware that faeces are being passed.

Types of urinary incontinence (Great Ormond Street Hospital 2017):

- *Stress urinary incontinence* (the involuntary leakage of urine on coughing, sneezing or on physical effort such as exercise);
- *Urge urinary incontinence* (associated with a sudden, unexpected and intense urge to pass urine);
- *Overflow* (due to an inability to fully empty the bladder);
- *Mixed* (a combination of different types of urinary incontinence);
- In children, urinary incontinence at night is also known as ‘*bedwetting*’, or ‘*enuresis*’.

Social, or functional, incontinence is when a person experiences leakage of urinary or faecal matter due to not being able to get to the toilet in time (due to, for example, mobility difficulties and/or, poor design that means that the toilet is difficult to access), or not wanting to use the toilet facilities available (for example, because they do not provide adequate privacy, or due to fear of violence on the way to the toilet or at the toilet facilities) (Ryan 2018).

Who might experience incontinence?

Some people experience incontinence due to being born with a malfunctioning bladder and/or bowel, but anyone at any age can also experience some form of incontinence. People at an increased risk of incontinence include:

Older people, particularly people living with dementia

Post-menopausal women (women whose menstruation has permanently ceased)

Perimenopausal women (women who are going through the transition to menopause, being when menstruation permanently ceases)

People with certain types of illness (such as cancer, diabetes, arthritis, asthma), or after an operation (such as men after the removal of the prostate)

People with neurological conditions (such as a spinal cord injury causing some degree of paralysis, brain injury and some nervous system disorders such as epilepsy), as well as immune-system disorders (such as Multiple Sclerosis)

People with physical and mental health conditions, such as intellectual (such as autism) and / or psychosocial disabilities (such as depression)

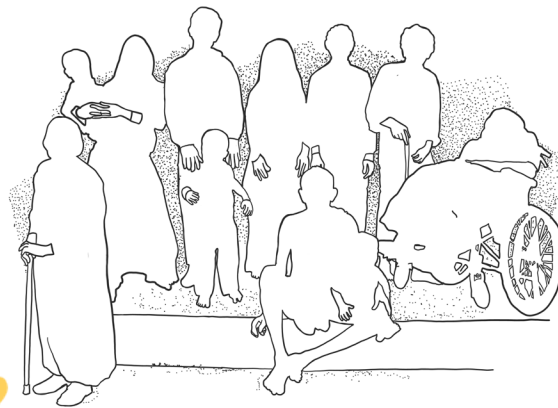
Many (but not all) people who have an increased risk of incontinence may commonly be part of groups of people already considered as vulnerable or disadvantaged by development actors.

People who have experienced highly stressful situations, such as conflict or disasters. Stress and anxiety have been found to contribute to bedwetting in some children

Pregnant adolescent girls and women

Adolescent girls and women who have given birth

All genders, at any age, can experience incontinence



Obstetric fistulas: an obstetric fistula is an abnormal opening between the vagina and bladder and/or colon through which urine or faeces leak out. Adolescent girls and women may suffer an obstetric fistula due to a prolonged and/or obstructed childbirth (often due to giving birth young), or from sexual assault.

People who have faced violent assault, including rape leading to fistula

Note that women, men, girls, boys and people of all genders can face violent assault, including rape.

People who abuse or overuse alcohol or drugs

Source: Authors own. References: Steers and Lee 2001; Hafskjold *et al.* 2016; White *et al.* 2016; Nevéus 2017; Niemczyk *et al.* 2018; Bhakta 2019; Mayo Clinic 2019; Choden and House 2019; Fistula Care Plus 2020; Alzheimer's Society 2020; WebMD 2020

The examples below highlight that people of all genders at any age can experience incontinence:

People with epilepsy:

people with epilepsy commonly experience urinary or faecal incontinence while having a seizure:

“Let’s say within the night I have seizures but there is limited water. That means I cannot wash my body and clothes properly so this is a major challenge. It means there are a number of people who you can tell have epilepsy because of how they smell...It’s a tough moment for me.”

(Man 27, Epilepsy. Urban.) (White et al. 2016)

Perimenopausal women:

as women pass through perimenopause (the transition to menopause which is when menstruation permanently ceases) concerns over menstrual health and hygiene gradually shift to urinary incontinence and the erratic patterns of menstruation are replaced by urine leaks or increased urges to urinate (Bhakta 2019):

“I visit the toilet more often to urinate, if I have not taken my bath I go to the toilet but after taking a bath I just take a chamber [pot] to the bathhouse if I want to urinate and after urinating I pour it down the drain.”

(Oheama, a perimenopausal woman from Kumasi, Ghana) (Bhakta 2019)

Older people:

older people, and especially older women, can experience incontinence due to, for example, weaker pelvic floor muscles or weaker bladder muscles (National Institute on Aging 2017):

“I was in India to see [an event to trigger community interest in ending open-defecation] ... Instead of depositing the pile of sand in one place to show where she goes to the toilet, one older woman walked around the map trailing the coloured sand behind her. The rest of the group said she must have misunderstood what she was asked to do, but the woman said no, she understood it, but this is what happens to her as she walks around the community.”

(S. Cavill)



The map the woman walked around. Credit: Sue Cavill

People with dementia:

a person with dementia is more likely to experience incontinence than a person of the same age who doesn't have dementia due to not being able to react quickly enough to the sensation of needing to use the toilet, or forgetting where the toilet is located (Alzheimer's Society 2020):

“I still think it’s to do with my dementia as I just can’t... I don’t get a signal that I need to go to the toilet, until I’m verging on... that I can’t move. I find this problem when I’m out shopping or out anywhere as many know, there’s no, not many public toilets now, and most that are I don’t think I’d like to use.”

(Dory, who lives with dementia in the UK) (Dementia Diaries 2020)

Adolescent girls and women with obstetric fistula:

unlike many causes of incontinence, most obstetric fistulas can be repaired through surgery and if successful incontinence may no longer be experienced (Khisa et al. 2017):

“Now [post-surgery] I don’t use pads anymore. Although the skin burns are not healed completely, it’s a small thing compared with the hell where I have come from. At night I sleep like a baby, no worries, no anxieties, no shame of washing my bedding every day. It is a whole freeworld.”

(Darling, post-obstetric fistula repair in Kenya) (Khisa et al. 2017)

Box 3: Incontinence and disability

Globally, there are an estimated 1 billion people with disabilities (approximately 15 per cent of the world's population) (World Health Organisation 2011). Not all people with disabilities experience incontinence. But people with disabilities may be at a greater risk of experiencing it, because of issues related to underlying health conditions, such as spinal cord injury causing some degree of paralysis, some nervous system disorders, or some immune system disorders. A recent study in Vanuatu found that people with disabilities were twice as likely to experience urinary incontinence than people without disabilities (30 per cent versus 14 per cent), and more likely to experience faecal incontinence than people without disabilities (26 per cent versus 15 per cent) (International Centre for Evidence in Disability (ICED) 2020).

Some people with disabilities may experience leakages because they are unable to reach or access a latrine (White *et al.* 2016). For example, people with mobility limitations may not be able to reach facilities in time if they are far away, or the path to reach them is unsafe. People with difficulty seeing may struggle getting to the facility or have inaccessible WASH facilities, and people with difficulties hearing or understanding might be less able to communicate that they need to use facilities.

Disability is also associated with ageing. People who are older may rely on aging partners for support when bathing and toileting, but are not always able to get it when needed. In the Vanuatu study, people with disabilities were less able to wash themselves than people without disabilities. This potentially exposed them to additional stigma and isolation.

“When I drink too much water, then I’ll urinate too much and my wife gets angry because she already washed for me”

(Male, walking, remembering functional limitations) (International Centre for Evidence in Disability (ICED) 2020).



What are the impacts of experiencing incontinence, or caring for people that do?

The consequences of experiencing incontinence, or caring for people that do, are far-reaching and can be categorised as 1) health and hygiene impacts; 2) mental health, emotional and social impacts; 3) practical and financial impacts; and 4) protection risks.

1. Health and hygiene impacts

a. A person that lives with incontinence can experience the following, some of which can become life-threatening:

Table 1: Health and hygiene impacts

IMPACT	FURTHER INFORMATION
Incontinence associated dermatitis (IAD; similar to nappy rash), skin infections and pressure sores due to prolonged exposure to urine and/or faeces (particularly when using adult diapers) and poor hygiene.	 <ul style="list-style-type: none"> It is important to monitor the skin for any redness, swelling or skin breakages that could be an early sign of a pressure sore. Advise individuals and households to seek medical attention immediately if any of these things occur. In addition, it is important to change diapers and/or the position of the individual regularly.
Urinary tract infections (particularly when using catheters) and bladder complications.	 <ul style="list-style-type: none"> A person who experiences barriers to communication may not be able to say when they are feeling pain or discomfort. Advise households to look for other signs of discomfort, such as unusual crying or tremors, that could be a sign of a health condition, such as a urinary tract infection. In addition, it is important to change catheters regularly.

IMPACT	FURTHER INFORMATION
Dehydration and constipation due to withholding food and liquid to reduce leakage.	Some people may not have a bowel movement for over a week and/or may not have enough water and other fluids for the body to carry out its normal functions (HelpAge and House 2019; Mayo Clinic 2020).
Physical accidents when trying to use toilets that are difficult to access. This is a risk particularly for, but not limited to, people with disabilities and elderly people. The consequences of such accidents could affect a person's ability to use a toilet.	Accidents trying to access toilets in Bhutan <i>“An older woman with a disability, was found in a very poor condition, living in very poor conditions, drunk, sleeping in a blanket covered with her faeces and urine. She was in no condition to talk but the team found out from the neighbours who were taking care of her that she is a kidu recipient (destitute allowance recipient) and the neighbours take turns to feed her. The team also found out that she used to be able to use her pit toilet which is not that far from the hut she lives in, but she had an accident while going to the toilet in the rain and had hurt herself, and since then she had been defecating and urinating in her sleeping room/the only room in her hut”</i> (Choden and House 2019).
Having to eat, bathe and toilet in one room which is unhygienic.	Without bedpans or commodes people who are unable to sit unaided out of bed and who experience incontinence may sit/balance on a bucket, which is placed next to their beds. If a bucket latrine or bedpan is uncovered, the user, carer and family members risk exposure to pathogens in the faeces, which can pose serious health risks including typhoid, diarrhoea and cholera. The user can also fall off the bucket risking injury.

Source: Authors own.

b. Caregivers may also experience health and hygiene impacts

If caregivers need to move the person experiencing incontinence to go to the toilet or to bathe they may suffer from back and associated problems especially if lifting devices aren't available (and few are available in LMICs) (Ansari 2017).

c. Incontinence and the transmission of diarrhoeal diseases

Although evidence is lacking, it is reasonable to assume that households with people with incontinence may have higher rates of diarrhoeal diseases due to the challenges of managing hygiene within the household and their higher demand for water and soap.

Challenges faced by caregivers in Vanuatu

“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.”

(Carer interview for woman with walking, remembering, self-care limitations, Vanuatu) (International Centre for Evidence in Disability (ICED) 2020)

Health problems in Malawi

“The toilet problem is a serious problem because if I open bowels or suffer from diarrhoea, I defecate where I am and they clean me ... it becomes a health problem to other people around me.”

(Woman, 78, arthritis and spinal curvature. Peri-urban) (White *et al.* 2016)

2. Mental health, emotional and social impacts

Incontinence can often be associated with stigma, but it can be a mixed picture. Research conducted in Zambia found that attitudes to incontinence were dependent on an understanding of the cause: when the condition was clearly the result of an underlying illness or injury, family members and the wider community tended to be relatively more supportive than if causation was believed to be related to sexual relations. For women especially, incontinence could rarely be discussed freely, particularly when the condition was due to pregnancy or childbirth (Rosato-Scott and Barrington 2018).

Where incontinence is associated with stigma and remains a taboo subject, people that experience incontinence, or who care for people that do, may:

- Feel shy to talk about it (Gjerde *et al.* 2013);
- Feel ashamed and embarrassed, particularly if they need support to manage their leakage and soiling of bedding and/or clothes (Gjerde *et al.* 2013);
- Experience a loss of self-esteem, for example due to feeling a loss of control and/or issues related to cleanliness (Hafskjold *et al.* 2016);
- Be bullied and/or teased, (which exacerbates shame, embarrassment and loss of self-esteem) (Theunis *et al.* 2002);
- Experience anxiety and depression (Wood and Anger 2014); and
- Limit their participation in, or even be excluded from, personal relations, social life and community life.

All these factors can exacerbate vulnerability and add to feelings of isolation and loneliness.

Exclusion in Pakistan

“I can’t sit with them. I have some friends but most of them left me and made me feel even more lonely and sad. I feel upset seeing them move around and sit together laughing and smoking. I sit and cry but then I don’t want people to see me cry so I try and hold my tears back. They go off to the city, especially Thar, where we used to work and they harvest. You know, it is harvest season? We used to have so much fun in harvest season and now I can’t even work.”

(Ansari 2017)



Credit: PhotoVoice photo by Poonmo, who has a disability and experiences incontinence

3. Practical and financial impacts

People who experience incontinence, or who care for people that do, may find it difficult to (Hafskjold *et al.* 2016):

- Access a toilet at short notice, or access a toilet at all;
- Access and afford sufficient soap and water to manage the incontinence hygienically and with dignity;

Managing incontinence requires significantly extra water and soap (estimated at five times as much as a person without incontinence), and time to bathe and wash clothes, bedding and pads (Sphere Association 2018). The reality of this for water collection alone is huge: many people spend a significant amount of time collecting water for the family, sometimes from a distance; and if people with incontinence are not able to collect water, they may need to pay someone to carry the water for them. In such circumstances, social support systems may need to be established to ensure that water needs can be met. Challenges to access and affordability of water may also be seasonal, for example, when water is scarcer and/or the weather is hotter the impact of incontinence on personal health and hygiene may be greater.

Credit: PhotoVoice photo by Poonmo, who has a disability and experiences incontinence

Water collection in Pakistan

“My sister goes to collect water two to three times a day. She has to walk about half an hour one way and so it takes her almost an hour to come back to me. We use that water to wash clothes and to clean myself. There is never enough water to make me feel clean. Many times I have been dirty and there has been no water in the house, so I have to sit in the filth until someone goes to the water point and brings some water back for me. I really need more water. If I had all this access to water, I would feel better because I would be cleaner.”

(Ansari 2017)



Barriers to accessing WASH for disabled people in Malawi

“Those who could not afford to use kiosks relied on unimproved water sources such as rivers and shallow, hand-dug wells. These participants were more concerned by the consequences for their safety and health. One example was a household with a boy of 14 who had an intellectual impairment. The boy was incontinent and required family members to wash him and his clothes regularly. The amount of water and soap they required as a household was much greater than neighbouring families. Consequently the family was unable to afford their piped water bills and had to make water and hygiene compromises”

(White et al. 2016).

Barriers include the ability to:

- Access and afford incontinence products, including pads, mattress covers, bedpans, etc;
- Wash, dry and store clothes, bedding and pads or other materials used to soak up urine or faeces safely and discretely;
- Dispose of soiled pads safely and discretely; and
- Participate in livelihood activities.

People that experience incontinence, or who care for people that do, may find it difficult to attend school or earn an income or self-exclude themselves from these opportunities (e.g. due to a lack of time, or embarrassment). People with incontinence may also self-exclude themselves from attending school or earning an income (due to, for example, the practical difficulties of managing the condition, or concern over other people noticing leakage or being able to smell leakage odour).

Items to help manage incontinence need to be: effective; culturally, gender- and size-appropriate; and desirable for use. Such items may be limited, or non-existent. Even if they are available, they may be costly and outside of the financial capacity of the household.

Limited levels of participation in Vanuatu and Uganda

“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 public 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.”

(man, walking and self-care functional limitation, Vanuatu)
(International Centre for Evidence in Disability (ICED) 2020)

“I am a councillor for the disabled... I was [once] in a meeting...I couldn’t go to the latrine yet I had gotten an urgent call. I tried enduring but ended up urinating on myself. I felt so humiliated that I have never gone back for a single meeting.”

(Man with disabilities, Uganda) (Wilbur et al. 2013)

4. Protection risks

People who experience incontinence may suffer abuse, including verbal punishment and physical violence.

Box 4: Examples of potential protection risks

- **Traditional practices** used to try and prevent incontinence. Such practices vary between communities: in one community in Nigeria the legs and genitals of a young girl who could not stop bed wetting were burned by making her stand over an open fire, elsewhere another was made to sit on a termite mound so that she would be bitten. In both cases the aim was that they would sting/hurt when urinating at night which would wake them up (Direct testimonies collected by House, S).
- **Anger and frustration felt by carers** which can lead to beating, shaming in front of other people, and punishment, for example making a person sleep on a bare floor instead of a mattress. Older

people face a high level of abuse in normal circumstances, and the risk of abuse is likely exacerbated if they also experience incontinence, for example, due to the increased daily workload of caregivers. (Ostaszkiwicz 2018; HelpAge and House 2019; and direct testimonies collected by House, S). Children and adolescents who wet themselves may also be particularly vulnerable to abuse (Sapi *et al.* 2009).

How many people might experience incontinence?

Estimating the global prevalence of incontinence is challenging: numerous studies have been completed, but comparison is rarely possible because study designs use varying definitions, study populations, and methodologies. International Consultations on Incontinence review general population studies (largely based in high-income countries) and find that (Buckley and Lapitan 2010; Abrams *et al.* 2017):

- 36 general population studies in 17 countries found prevalence estimates for 'any' urinary incontinence of all types in women ranging from 5 to 69 per cent, with most studies within 25 to 45 per cent;
- Prevalence rates for 'any' urinary incontinence in men ranging from 1 to 39 per cent have been published;
- The prevalence of daytime urinary incontinence in children decreases with age (from 3.2 to 9.0 per cent in seven-year olds, to 1.1 to 3.0 per cent in 15 to 17-year olds), as does bedwetting (from 6.8 to 16.4 per cent at seven years of age, to 0.5 to 1.7 per cent by age 16-17 years); and
- Studies tend to report that less than 15 per cent of adults have faecal incontinence.

Data for LMICs is lacking, but figures could be higher due to a higher number of young mothers and a lack of maternity services. Examples include:

- A systematic review of research from only low- and lower-middle-income

countries found among a sample of women who had given birth, the mean prevalence of urinary incontinence was 29 per cent, and of faecal incontinence was 7 per cent (Walker and Gunasekera 2011);

- The World Health Organization (WHO) estimates that more than 2 million women live with untreated obstetric faecal fistula in Asia and sub-Saharan Africa, and 50,000 to 100,000 new cases occur each year (World Health Organisation 2018). In Bangladesh it is estimated that 0.17 per cent of married women (around 70,000 women) suffer from an obstetric fistula (Akter 2019);
- A 2020 study in Vanuatu found that 32 per cent of people with disabilities and 13 per cent of people without disabilities reported experiencing urinary incontinence, and 30 per cent of people with disabilities and 16 per cent of people without disabilities reported experiencing faecal incontinence (International Centre for Evidence in Disability (ICED) 2020).

Challenges to identifying people that experience incontinence, or who care for people that do

Speaking to people who are living with incontinence and understanding their lived reality is the first step to being able to find solutions. For the WASH sector to know what support to provide, it first needs to reach the people living with incontinence and ask them what their priority needs are. Challenges that may be faced when trying to identify people that experience incontinence include:

- The term 'incontinence' or its local translation (where an equivalent word exists) may not be understood, even by health professionals;
- Incontinence can be a sensitive and highly stigmatising issue that people may not feel comfortable talking about, even with their family and friends;
- People that experience incontinence may face, or fear facing, increased stigma, bullying and/or teasing if other people know about their condition;
- People may be reluctant to discuss incontinence symptoms as they do not believe there are treatment options available (Rosato-Scott and Barrington 2018).

People that experience incontinence may also not perceive that they have a health condition that needs to be discussed because, for example:

- They feel that they are managing the condition sufficiently. For example, they may be able to use toilets at home and in public may rarely be far from a toilet and can therefore manage the leakage (Rosato-Scott and Barrington 2018).
- Incontinence is viewed as a 'natural' part of aging / postnatal health and people with incontinence may feel that they don't need more support;
- Local culture expects a high level of resilience to pain and suffering, and experiencing incontinence is therefore regarded as a challenge to be silently managed (Rosato-Scott and Barrington 2018).



Strategies for the WASH sector to engage with people that experience incontinence, or who care for people that do

As living with incontinence is a sensitive issue, it is likely that people who are living with it may not be well known at community level as they do not talk about the condition. To identify people living with incontinence and facing challenges, it can be helpful to work with broader groups of people with characteristics that may make them more vulnerable to the condition, for example, mothers; people with disabilities; and older people.

Specific actors for the WASH sector to engage with who may also be helpful to identify people living with incontinence and facing challenges due to experiencing the condition, may include:

- Community leaders who may know of families who are struggling;
- Community health workers, community development workers; and community outreach teams, including health promotion teams going house to house;
- Disability specialist organisations, occupational therapists, community rehabilitation services and carer support groups;

- Organisations who support people who may be particularly disadvantaged, for example people living with chronic health conditions such as HIV;
- Religious leaders;
- Teachers in schools and child-friendly spaces; and
- Women's groups and older person's networks.

Community members may also raise this issue in different contexts. For example, by asking general questions in focus group discussions about incontinence, a participant may indicate that they know someone who is living with incontinence. It is important not to ask the participant to name the person living with incontinence during the group discussion, but to focus on the general challenges that people living with incontinence may face. But if it is felt appropriate the participant can be asked (discretely and privately afterwards) if they would be willing to ask the person living with incontinence if they would be interested in having a conversation about the condition with you or an alternative person they feel comfortable with. If the person living with incontinence is willing to talk, ask to be introduced and follow the 'Talking about leaks' guidance.

Strategies to encourage self-referral may also be used where specific services are functioning. For example, posters advertising support centres for people with fistulas (see [p30](#), Zambia poster).



Talking about leaks

Understanding incontinence requires having conversations with individuals that experience the condition, *and* with individuals who care for those that do. Some people may be keen to talk about their experiences with incontinence due to, for example, not often having the opportunity to do so. Yet some people may initially find it challenging to have conversations about the condition, although the more times they do speak about it, the easier it may become. Incontinence is a topic that is best suited to in-depth discussions, which are flexible in structure and guided by the participant rather than a structured interview or survey process.

There are a number of ways to reduce any embarrassment or discomfort:

- Ensure that you have a basic level of understanding of incontinence and its management which you can explain in simple terms using culturally appropriate language (using simple language is always a good strategy in general);
- Have men speaking with men, and women speaking with women when possible;
- Check if the interviewee would like to have anyone specifically present or absent;
- Make sure that discussions are held in a comfortable, private location where other people cannot hear;
- Be confident and do not show embarrassment yourself;
- Put the person at ease and build trust by being friendly and building rapport, by discussing some easier subjects first, for example the person's family and general WASH facility access;
- Use active listening skills, such as nodding and expressing supportive statements to encourage people to talk; and
- Ask permission before asking questions on incontinence, and explain why you would like to discuss the issue. Explain that a lot of people experience the condition, but few talk about it, and that we need to speak with people who experience incontinence to understand the challenges and what we can do to support them better. Emphasise that this is a safe place to speak, and if they do not want to answer any question then they do not have to and nothing bad will happen. Also explain how the information provided will be used.

Note that:

- ! The person asking the questions should also try to not imply that such experiences are necessarily problematic, without the person themselves saying so.
- ! When exploring what kind of challenges people who are living with incontinence are facing and what support might be useful, it is good practice to have some options for support already identified, even if they

are an interim nature that can be given to them shortly after the discussion with them, while other resources are sourced. For example, for the provision of extra buckets, soap or a commode chair, or to have contact details to assist the person and their caregiver to be linked to the health facility.

- ! It may also be useful to take helpful resources with you (for example, sample reusable pads or underwear, examples of urine containers or mattress protectors and/or documents about how to make pads which are tailored to the recipient and easily understood). This is so that they can look at the options and discuss what would be most useful. The opportunity for the person to have a sustainable supply should also be considered before deciding whether to take such resources or not.
- ! For both of the two points above, the discussion and the supply process should be done discretely, so that the person themselves can decide if such items would be positive for their management of incontinence and receive support, and not cause more problems by making their incontinence more prominent to others.
- ! Discussions about incontinence may result in the people who are living with incontinence sharing information that requires support that is wider than the WASH sector can provide, for example if it becomes apparent that there has been some historic or ongoing abuse, or mental illness. Before having any discussions about incontinence, ensure that you have the contact details (including telephone numbers and addresses) of referral services that can be left with the person, or that can be contacted on the person's behalf with the person's permission.

Box 5: "Incontinence isn't an issue – it wasn't mentioned during community consultation"

Don't assume that incontinence isn't an issue just because it didn't arise when conducting formative research or during programme development – incontinence is a very sensitive topic which people often go to great lengths to keep hidden. It is important that throughout implementation the WASH sector continues to consider incontinence as a potential issue, learn from health professionals aware of people living with it, or community members affected by it, to gain a better understanding, and adapt practice as necessary if issues of incontinence do arise.

To be able to ask questions about incontinence, the following phrases may be useful, using culturally appropriate words where applicable (Ansari 2017):

- *Are you able to control your urine or faeces / is it difficult for you to control your urine or faeces / do you have the capacity to control your urine or faeces / do you face problems dealing with your urine or faeces?*
- *Can you hold onto your urine or faeces / do you have difficulty or problems holding in your urine or faeces / can you hold onto your urine or faeces?*
- *Does your urine or faeces sometimes come out involuntarily / does your urine or faeces sometimes come out when you don't want it to / do you ever leak urine or faeces / does your urine or faeces ever just come out?*
- *Has it ever happened to you that your urine or faeces came out before you managed to reach the bathroom / can you always get to the toilet on time / have you ever wet yourself / have you ever soiled yourself?*
- *(In settings with majority Muslim populations) Does your absolution for prayer get broken without you wanting it to / do you have any problems or difficulty with staying clean for prayer?*
- *Is there someone in your family who is suffering from a bad or foul smell (or odour) / is there anyone in your family that smells of urine or faeces?*
- *(When speaking to a caregiver) Where does (for example, your child) usually urinate / defecate, in the day / at night?*

Box 6: Discussing sensitive topics

Before asking questions about incontinence, or other potentially sensitive topics, we always need to consider how we, or someone we care about, would feel being asked. Sometimes as WASH professionals we distance ourselves emotionally from the situations we work in, as a form of self-preservation. But it's always useful to think about how we would react to questions being phrased in a certain way if they were directed at us, and let this guide an empathetic way of asking about potentially embarrassing or sensitive topics.

Box 7: PhotoVoice

PhotoVoice can be a useful technique to encourage people to share their experiences of taboo topics such as incontinence. PhotoVoice is a participatory technique which allows people to be given a camera to take photographs to illustrate their lives, and to enable other people to understand their issues (Blackman and Fairey 2014). The photographs produced from PhotoVoice can encourage participants to reflect on their experiences, and to share these experiences to raise awareness of their issues. Photographs produced from PhotoVoice are often shared with the wider community and policy makers through exhibitions and public events (Fantini 2017). Note that particular care is needed to consider the issues around obtaining consent for the taking and using of photos.

PhotoVoice has been used in different contexts to understand the needs of people with incontinence. Ansari (2017) used PhotoVoice to explore the impact of incontinence on people with disabilities and their caregivers in Sindh, Pakistan and Wilbur (Bhakta and Wilbur 2019) explored the needs of people with incontinence in Vanuatu using PhotoVoice: examples of both can be found in this issue of *Frontiers of Sanitation*.

More information and practical advice on using PhotoVoice to explore incontinence and other topics can be found in a *Sanitation Learning Hub Learning Brief*, '[The use of PhotoVoice in the WASH sector](#)' (Bhakta 2020).



Credit: PhotoVoice photo by Bahadur Mohammad Yaqoob Unar, who has a disability and experiences incontinence

Ant on foot, Pakistan

“You see the ant on my foot. There are constantly ants and flies crawling all over my body, but I can't feel them or shake them off. It is hot and that is why the ants are there, but I can tell you why the flies are present and that is what makes me the most uncomfortable and sad. I can't keep myself clean and because I can't be clean, the flies come and sit on me all day. No matter how much we clean the area around me, the smell and dirt remains and then the flies come and sit on me. They know when I am dirty” (Ansari 2017).

How can the WASH sector support people who experience incontinence, or who care for people that do?

All people that experience incontinence have significantly increased needs for water supply and for accessible, private WASH facilities. For people who already commonly face substantial barriers to accessing adequate WASH, including people with disabilities and people with underlying vulnerabilities such as homelessness or poverty, the experiences and challenges of living with incontinence can be exacerbated. For example, we know that people with disabilities often have less adequate access to WASH services than people without disabilities (United Nations 2018). 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 (United Nations 2018; Mactaggart *et al.* 2018).

Inclusive, accessible WASH for people should always be kept in mind when considering incontinence and its impact. The WASH sector should ensure that people who are unable to control their bladder or bowel have easy access to water supply and sanitation facilities, and are able to manage their hygiene safely and with dignity. Actions to be undertaken include **1) raising awareness and challenging myths; 2) ensuring accessible water supply and sanitation facilities; 3) ensuring a sustainable supply of basic hygiene items; and 4) providing products to aid the management of leakage.**

1. Raise awareness and challenge myths

In some languages there may not be an equivalent word for ‘incontinence’. Even when the term is explained, people may still not know what incontinence is, including some health professionals (Rosato-Scott and Barrington 2018).

“So that’s it, that embarrassing issue of incontinence. If we keep saying it... Incontinence... Incontinence... Incontinence, then you know, maybe the message will get out there.”

(Carol, who lives with dementia in the UK) (Dementia Diaries 2020)

There are also many myths and misconceptions about incontinence. These may be culturally specific, for example, incontinence can be viewed as ‘supernatural’ or a ‘curse’ and people that experience incontinence can therefore view themselves as “*abnormal*” and “*less human*” (Rosato-Scott and Barrington 2018).

To understand local attitudes about incontinence speak with (see ‘**Talking about leaks**’, [p23](#)):

- People that experience incontinence, or who care for people that do, and their wider families (but only if permission from the person experiencing incontinence is first obtained) (see ‘**Strategies for the WASH sector to engage with people that experience incontinence, or who care for people that do**’ [p22](#));
- The wider community;
- Community leaders, including religious leaders and teachers;
- Health practitioners (including those practicing traditional medicine);
- Protection, gender, gender-based violence, disability and age sector actors;
- Government and non-governmental organisation (NGO) officials, managers and practitioners.

To de-mystify and de-stigmatise incontinence, raise awareness with the same groups of people, emphasising in conversations, guidance documents and other publications where appropriate that:

- Incontinence is not a condition to be ashamed about. It happens to a wide range of people and needs to be discussed if we are going to be able to identify options for support;
- The challenges and risks faced by people that experience incontinence, particularly the risk to the right of every person to live a life with dignity, the potential health impacts including the risk of death, and the protection risks;
- The additional WASH needs of people who experience incontinence, or who care for people that do;
- For some conditions health care professionals, including occupational therapists, may be able to improve symptoms; and
- The availability of fistula surgery and its life-changing impact.



What is a fistula?

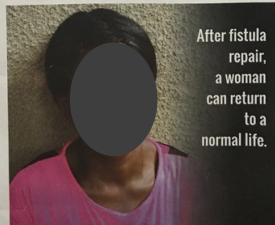
- Obstetric fistula is a hole between the vagina and bladder or rectum
- It is most often caused by prolonged obstructed labour when a woman labors for hours or days without medical intervention

What are the symptoms of fistula?

- A woman who has fistula leaks urine or feces continuously all day and night and she cannot stop it nor control it
- She wets or soils her clothes frequently and has a strong smell associated with the leaking

Fistula is stigmatizing

- Many women with fistula are isolated due to the shame caused by the condition
- Fistula is not a curse and women should be supported to seek treatment



Fistula can be treated

- Fistula can be treated by a trained doctor. You don't need herbs to cure fistula.
- A woman with fistula should seek medical care immediately at a hospital that offers fistula treatment services, including:
 - Chilonga Mission Hospital
 - Kabwe General Hospital
 - Mansa General Hospital
 - Monze Mission Hospital
 - University Teaching Hospital

Fistula Foundation supports women with fistula to be treated free of charge and pays for transport to and from the facility. Women with fistula will also receive essential items such as soap, chitenge, and body lotion.

Call this number for free screening and referral:
096 9 934410

Fistula awareness in Zambia

A fistula poster at University Teaching Hospital, Lusaka, Zambia. The poster explains what a fistula is and the treatment options available, and also emphasises that having a fistula is not something to be embarrassed about.

(Rosato-Scott and Barrington 2018. *Photo credit:* authors own)

sanitation, which can be used when it is needed. Note that toileting times for a person with incontinence need to be consistent with the household routine, but care should be taken to make sure that the person is not forced to use, or is made fearful of using, the toilet. People with incontinence should always feel safe and confident to use the toilet regularly.

Some people with incontinence may not need the support of a carer to use the toilet, but still need to be able to relieve themselves and to change soiled continence products, any time day or night. Accessible sanitation inside the household is the ideal way to ensure that people with incontinence can manage their needs effectively. Community based toilets need to be easy to access at any time, ensure the safety of users (for all users, but especially women and girls who are particularly at risk of gender-based violence), and provide privacy for people who experience incontinence to manage their needs with dignity (UNICEF *et al.* 2018).

b. Sanitation infrastructure designed to be used by people with ease

Sanitation facilities (toilets, bathing and laundry facilities) and related equipment such as commodes need to be designed and built so that they are physically accessible and can be used easily. Accessible sanitation can be provided through the following measures (Jones and Wilbur 2014; Wilbur and Jones 2014):

- Considering (in terms of distance, location and cultural appropriateness) where to safely position sanitation facilities.
- Ensure a sufficient supply of water to all sanitation facilities.
- Ensuring an accessible approach to the facilities. Signs to the facilities should be well-lit and use simple communication methods. Paths need to be wide enough for two people to use side by side (e.g. a caregiver and person living with incontinence), clear and level so that people with physical impairments, wheelchair users or people who have visual impairments can reach the facilities easily. Landmark posts or rocks along the path can be painted to aid visibility. A guide rope along the path can also help people with visual impairments to reach the facilities. Level access at the entrance to toilets should be provided, with a wide enough entrance for a wheelchair.
- When communal/public facilities are supported, they should be separated by gender, by providing screening or by building men's/boys' and women's/girls' facilities a distance away from each other. It is also good practice to provide

2. Ensure accessible water supply and sanitation facilities

Accessible water supply and sanitation is important for meeting the needs of people with incontinence. Water supply and sanitation are 'accessible' if: facilities are available for people who are living with incontinence to access and use regularly; and the infrastructure is designed to be used by all people with ease.

a. Regular access to sanitation

Note that some people with incontinence may not be able to use the toilet at all. Products are available to support the management of incontinence in such circumstances: see '4. Products to aid the management of incontinence' for further details (p34).

For people who are unable to control their bladder and/or bowel movements and who require care, it is important for carers to establish a regular toilet routine. But establishing a regular toilet routine needs regular access to

an additional facility that anyone of any gender can choose to use, which is accessible and large enough for a caregiver and child to use.

- Ensuring that doors to the facilities are robust but not too heavy, and that handles are easy to reach and use. D-shape lever door handles are easier to use than doorknobs.
- Accessible locks which are easy to reach, open and close. These can include a bolt with a large handle, or a piece of string which can be hooked around nails, a metal hook or a post.
- Fixed and fold-down handrails, so that users have a choice of support options.
- Hooks and shelves can make it easier for people with incontinence to effectively change soiled incontinence products and clothing, with dignity and privacy by providing somewhere to hang clothes and put pads and other items on.
- Discrete disposal facilities for disposing of soiled disposable incontinence materials. Options could include a container with a lid located within the toilet, or a chute from the toilet to an incinerator (World Vision and CBM Australia 2018). When considering such facilities, the whole collection and disposal chain also needs to be considered, including collection, transfer and disposal (with general refuse, burning or burial). Note that information on the disposal, management and laundering of menstrual waste may be useful (Schmitt *et al.* 2020 for example).
- Water taps and washbasins should be positioned at a suitable height for a wheelchair user and with unobstructed knee clearance for wheelchair users. Ensure that taps are robust but not too heavy and large taps with long levers are easier to operate. Locate soap for ease of use and where people with visual or mobility disabilities can easily find/reach it.
- *(Toilet specific)* Latrine holes which are larger than the standard size can make it easier to hit the hole when urinating, particularly if a person has difficulty squatting.
- *(Toilet specific)* A chair with a hole that a person can sit on over the latrine, or which has a container fixed underneath it. Care will be needed to ensure that the chair is easy to clean; and that it is stable when the person moves to sit on it, whilst they are sitting on it, and when standing up.
- *(Toilet specific)* Splash guards, to prevent urine and faecal matter from

splashing on to the user's legs or spilling onto the floor around the latrine.

- *(Toilet specific)* Commode chairs in the house or placed near to the bed of the person with incontinence, so that they can be reached if the person has a sudden urge to urinate or defecate, but cannot reach the toilet quickly enough to prevent an accident.
- *(Bathing and laundry facilities specific)* Ensure sufficient privacy to allow cleaning of self and soiled clothing and bedding.
- *(Bathing and laundry facilities specific)* Effective drainage is needed as the wastewater may be contaminated with faeces if used by people living with faecal incontinence.
- Materials used to construct sanitation facilities should be easily cleanable (for example cement, varnished or painted wood, metal, plastic).
- Sanitation facilities should be maintained and regularly cleaned.

c. Water supply infrastructure designed to be used by people with ease

Water supply facilities also need to be designed and built so that they are physically accessible and can be used easily. Accessible water supply can be provided through the following measures (Jones and Wilbur 2014; Wilbur and Jones 2014):

- Considering (in terms of distance, location and cultural appropriateness) where to safely position water supply facilities.
- Ensuring an accessible approach to the facilities as per for Sanitation Infrastructure above.

3. Ensure a sustainable supply of basic hygiene items and facilities

Ensuring personal cleanliness will likely be a priority for a person with incontinence. Other social factors can place an additional requirement to remain clean, such as to practice religion. Managing incontinence requires significantly extra water and soap (estimated at five times as much as a person without incontinence), and time to bathe and wash clothes, bedding and pads (Sphere Association 2018). A sustainable supply of basic hygiene items, and in particular soap and water containers, should therefore be available. Note that there may be local enterprises that could support the provision of such items.

“This makes me very happy and makes me feel clean. I use it all the time to manage my cleanliness and smell. It cleans my clothes and it cleans my hands and the most important thing is that it keeps me clean. I always make sure there is soap in the house and keep asking to check if it is still available, because I will never feel clean or smell normal.”
(Ansari 2017)



Credit: PhotoVoice photo by Bahadur Mohammad Yaqoob Unar, who has a disability and experiences incontinence


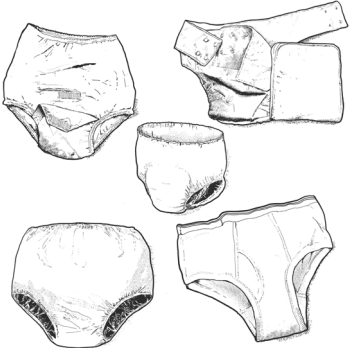
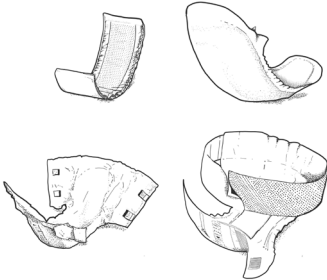
4. Products to aid the management of incontinence

The Continence Product Advisor website provides impartial advice on all products to aid the management of leakage (<https://www.continenceproductadvisor.org>). Note that not all guidance will be directly applicable in all circumstances: availability, suitability and individual preferences will vary. Most products have also been designed with high-income contexts in mind and therefore may need to be adapted to lower-income contexts.

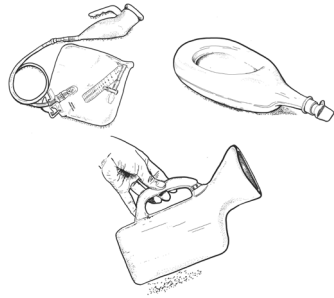
Options must be discussed with affected people to understand their preferences for disposable or reusable materials, laundry and drying facilities, and disposal mechanisms (in homes, schools, health centres and communal facilities) and products selected should be based on the opinions of the person with incontinence and their carer.

Table 2: Incontinence products

Product options include (R*: Reusable / D*: Disposable):

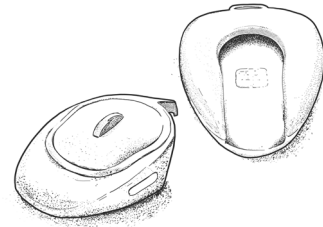
PRODUCT AND DESCRIPTION	R*	D*
<p>Mattress protector: To protect a mattress, made of an impermeable material (e.g. plastic).</p> 	✓	✓
<p>Underwear: Underwear with a thick portion for soaking up urine / faeces (placed in different positions for men and women), and/or have a pocket for inserting a pad. Can be pull-up, or wrap around fixed with velcro or poppers. See World Vision and CBM Australia (2018) for guidance to make reusable underwear, noting that towelling should not be used for the innermost layer as it is likely to be rough against the skin and will retain the liquids against the skin.</p> <p>Pull-up plastic outer pants to contain leakage are also an option.</p> <p><i>*To be used safely, underwear should be changed frequently*</i></p> 	✓	✓
<p>Inserts and pads: To absorb leakage. Can have tabs to secure into underwear.</p> <p><i>*To be used safely, inserts and pads should be changed frequently*</i></p> 	✓	✓

Handheld urinals: Used when access to a toilet is not possible or convenient. Containers are usually made from plastic, and different entrance shapes are needed for men and women.



✓	
✓	
✓	

Bedpan: Portable device for passing urine and/or faeces while lying down or sitting. Usually made from plastic.



Commode (portable toilet): Used by people with reduced mobility. Can be a) a container of some kind that slots into place under the seat plus lid, or b) a chute that goes down to a bucket or pit latrine hole, or c) a hole in a chair to place over a latrine hole.

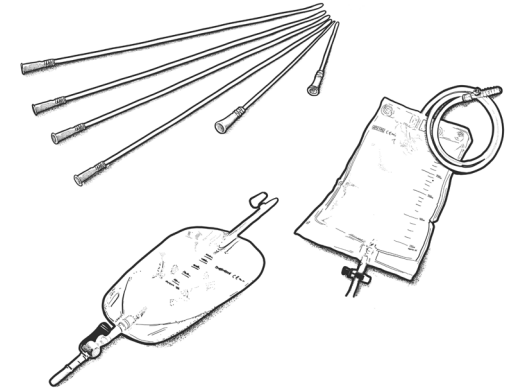


Source: Authors own.

There are also products available that must be used only under the supervision of a health professional:

! Moisture / barrier creams, which must not irritate the skin and must be suitable for children. Stop use immediately if there is broken skin or wounds (World Vision and CBM Australia 2018); and

! Some people may also find catheters and leg bags helpful, but there may be challenges with their use and they should only be provided and monitored by specialists with expertise in this area (health, disability, occupational therapists).



Top tips:

- Consider how supplies will be replenished, including who will buy them and how. This may include exploring options for small enterprises to provide materials or for people to make their own protection materials, or subsidies for families with a person with incontinence.
- Ensure that the users and family members understand how to use the items provided: in Bangladesh, it was reported that some children were seen using urine containers as water bottles (direct testimony shared in a cross-sectoral meeting on incontinence from a Rohingya refugee camp-based NGO worker).
- Care must also be taken to identify and agree safe mechanisms for the disposal of the urine or faeces from containers (handheld urinals, bedpans, commode chairs) and subsequent cleaning of the containers.

Recommendations

Talk about leaks: it is unethical for the WASH sector not to consider and learn about the challenges people living with incontinence may be facing, particularly if it is negatively impacting their life and where we can offer some practical advice or solutions to



Support people to live with dignity: people that experience incontinence will probably be making significant efforts in very difficult situations to manage the condition. We cannot assume to know what support is needed and appropriate, and therefore



Be a sensitive listener and talker: incontinence is a sensitive topic and people may be uncomfortable discussing it. Always consider the comfort of the people we talk to and “do no harm” when attempting to understand experiences with incontinence, talk in a private location and ask for permission to ask questions on it. A great first step is to



Normalise incontinence: advocate that incontinence is not a condition to be ashamed about, it happens to a wide range of people and there are options to improve the quality of life of those that experience it, or care for those that do. People may not know about this issue. Be prepared to



Challenge resistance across sectors: incontinence has a significant impact on the quality of life of people that experience the condition, or who care for people that do. Some health impacts can be life threatening, and the protection risks for people that experience incontinence can be higher relative to those that don't. Everyone working across sectors must coordinate and work together.

Learning and research priorities

As it is hoped that this resource will act as an advocacy tool to push the WASH sector to do more learning and research on incontinence in LMICs, a list of learning and research priorities has been provided:

- Awareness of and attitudes towards incontinence to better understand any stigmas associated with the condition (noting that these may be culturally specific). This understanding should inform the methods used to understand people's experiences of incontinence (see below);
- How to create opportunities to have conversations with people (of all ages and all genders) that experience incontinence or who care for people that do, and how to have such conversations, to best understand their personal experiences about the condition, given the stigma associated with incontinence and/or the lack of awareness about it;
- Water issues related to incontinence, including supply, demand, accessibility and affordability across seasons (that is, considering temperature and rainfall fluctuations); and considering for both individuals and across households;
- Toilet and bathing issues related to incontinence, including supply (for example, household versus community), demand, accessibility and affordability;
- How best to support the management of incontinence with products, including preferences; accessibility including sustainability of access; affordability; management when on the move (for example, refugee populations); and the role of small, local enterprises in the manufacture of products;
- Traditional practices related to incontinence, including the role of traditional medicine in management and treatment;
- Protection issues related to incontinence and how to prevent them;
- Faecal incontinence and disease transmission (that is, through faecal matter);
- The validation of tools and definitions to measure the prevalence of urinary and/or faecal incontinence; and then using such tools, the prevalence of incontinence considering all ages; all genders; and all contexts.

References

- Abrams, P., Cardozo, L., Wagg, A. and Wein, A. (eds.) (2017) *Incontinence* 6th Edition Bristol, UK: ICI-ICS. International Continence Society, accessed 14 October 2020
- Akter, F. (2019) *Incontinence in Female Genital Tract*
- Alzheimer's Society (2020) '[Toilet problems and continence](#)', accessed 25 September 2020
- Ansari, Z. (2017) *Understanding the Coping Mechanisms Employed by People with Disabilities and their Families to Manage Incontinence in Pakistan*, London: London School of Hygiene & Tropical Medicine
- Bhakta, A.N. (2019) *Opening the Doors to the Hidden Water, Sanitation and Hygiene Needs of Women from the Onset of the Perimenopause in Urban Ghana*, PhD thesis, Loughborough: Loughborough University, accessed 25 September 2020
- Bhakta, A.N. (2020) '[Uncovering WASH realities through PhotoVoice](#)', *SLH Learning Paper* 9, Brighton: IDS, accessed 14 October 2020
- Bhakta, A.N. and Wilbur, J. (2019) Personal communication, 26 September 2019
- Blackman, A. and Fairey, T. (2014) *The PhotoVoice Manual: A Guide to Designing and Running Participatory Photography Projects*, PhotoVoice
- Buckley, B.S. and Lapitan, M.C.M. (2010) 'Prevalence of urinary incontinence in men, women, and children-current evidence: Findings of the Fourth International Consultation on Incontinence', *Urology* 76.2: 265–270, <https://doi.org/10.1016/j.urology.2009.11.078>
- Choden, T. and House, S. (2019) *Leaving no-one Behind, National Rural Sanitation and Hygiene Programme (RSHAP) of Bhutan, Beyond the Finish Line Research Report, Sustainable Sanitation and Hygiene for All – Bhutan*, SNV Bhutan, accessed 14 October 2020
- Dementia Diaries (2020) '[Dementia Diaries](#)', accessed 4 June 2020
- Dumoulin, C., Hay-Smith, E.J.C. and Mac Habée-Séguin, G. (2014) '[Pelvic floor muscle training versus no treatment, or inactive control treatments, for urinary incontinence in women](#)', *Cochrane Database of Systematic Reviews*, 10, DOI: 10.1002/14651858.CD005654.pub4, accessed 14 October 2020
- Fantini, E. (2017) '[Picturing waters: A review of Photovoice and similar participatory visual research on water governance](#)', *WIREs Water*, 4.5: 1226, accessed 14 October 2020
- Fistula Care Plus (2020) '[Traumatic Fistula](#)', Fistula Care Plus, accessed 14 October 2020
- Gjerde, J.L., Rortveit, G., Muleta, M. and Blystad, A. (2013) 'Silently waiting to heal: Experiences among women living with urinary incontinence in northwest Ethiopia.', *International Urogynecological Journal*, 24: 953–958, DOI: 10.1007/s00192-012-1951-4
- Great Ormand Street Hospital (2017) '[Urinary incontinence](#)', Great Ormand Street Hospital, accessed 14 October 2020
- Guy's and St Thomas' (2014) '[Faecal incontinence: Advice from the Pelvic Floor Unit](#)', accessed 14 October 2020
- Hafskjold, B., Pop-Stefanija, B., Giles-Hansen, C., Weerts, E., Flynn, E., Wilbur, J., Brogan, K., Ackom, K., Farrington, M., Peuschel, M., Klaesener-Metzner, N., Cordero, R., Cavill, S. and House, S. (2016) 'Taking Stock: Incompetent at incontinence – why are we ignoring the needs of incontinence sufferers?', *Waterlines*, 35.3, DOI: 10.3362/1756-3488.2016.018
- HelpAge and House, S. (2019) Email correspondence
- International Centre for Evidence in Disability (ICED) (2020) *Water, Women and Disability Study Report*, London: ICED
- Jones, H. and Wilbur, J. (2014) '[Compendium of Accessible WASH Technologies](#)', WEDC, WaterAid and SHARE, accessed 14 October 2020
- Khisa, W., Wakasiaka, S., McGowan, L., Campbell, M. and Lavender, T. (2017) '[Understanding the lived experience of women before and after fistula repair: A qualitative study in Kenya](#)', *BJOG: An International Journal of Obstetrics and Gynaecology*, 124.3: 503–510
- Mactaggart, I., Schmidt, W.P., Bostoan, K., Chunga, J., Danquah, L., Halder, A.K., Parveen Jolly, S., Polack, S., Rahman, M., Snel, M., Kuper, H. and Biran, A. (2018) '[Access to water and sanitation among people with disabilities: Results from cross-sectional surveys in Bangladesh, Cameroon, India and Malawi](#)', *BMJ Open*, 8.6: 1–13, accessed 14 October 2020
- Mayo Clinic (2020) '[Dehydration](#)', accessed 14 October 2020
- Mayo Clinic (2019) '[Urinary Incontinence](#)', accessed 14 October 2020
- National Institute on Aging (2017) '[Urinary incontinence in older adults](#)', National Institute on Aging, accessed 14 October 2020
- Nevéus, T. (2017) '[Pathogenesis of enuresis: Towards a new understanding](#)', *International Journal of Urology*, 24.3: 174–182
- Niemczyk, J., Wagner, C. and von Gontard, A. (2018) 'Incontinence in autism spectrum disorder: a systematic review', *European Child and Adolescent Psychiatry*, 27.12: 1523–1537, DOI: 10.1007/s00787-017-1062-3
- Ostaszkiwicz, J. (2018) '[A conceptual model of the risk of elder abuse posed by incontinence and care dependence](#)', *International Journal of Older People Nursing*, 13.2, accessed 14 October 2020
- Rosato-Scott, C.A. and Barrington, D.J. (2018) 'Incontinence in Zambia: initial investigation into the coping strategies of sufferers and carers', *Waterlines*, 37.3: 190–206
- Ryan, F. (2018) '["It's horrifically painful": The disabled women forced into unnecessary surgery](#)', *The Guardian*, accessed 14 October 2020
- Sapi, M.C., Vasconcelos, J.S.P., Silva, F.G., Damião, R. and Da Silva, E.A. (2009) 'Assessment of domestic violence against children and adolescents with enuresis', *Jornal de Pediatria*, 85.5: 433–437, DOI: 10.2223/JPED.1935
- Schmitt, M., Clatworthy, D., Gruer, C. and Sommer, M. (2020) '[Menstrual Disposal, Waste](#)

[Management and Laundering in Emergencies: A Compendium](#), New York, Columbia University and International Rescue Committee, accessed 14 October 2020

Sphere Association (2018) 45. [The Sphere Handbook: Humanitarian Charter and Minimum Standards in Humanitarian Response](#), 4th ed. Geneva, Switzerland: Sphere Association, accessed 14 October 2020

Steers, W.D. and Lee, K.S. (2001) 'Depression and incontinence', *World Journal of Urology*, 19.5: 351–357, DOI: 10.1007/s003450100227

Theunis, M., Van Hoecke, E., Paesbrugge, S., Hoebeke, P. and Vande Walle, J. (2002) 'Self-image and performance in children with nocturnal enuresis', *European Urology*, 41.6: 660–667, accessed 14 October 2020

UNICEF, WaterAid and WSUP (2018) [Female-Friendly Public and Community Toilets: A Guide for Planners and Decision Makers](#), UNICEF, WaterAid and WSUP, accessed 14 October 2020

United Nations (2018) [Disability and Development Report: Realizing the Sustainable Development Goals by, for and with Persons with Disabilities](#), New York: United Nations, accessed 14 October 2020

Walker, G.J.A. and Gunasekera, P. (2011) 'Pelvic organ prolapse and incontinence in developing countries: review of prevalence and risk factors', *International Urogynecological Journal*, 22: 127–135, DOI: 10.1007/s00192-010-1215-0

WebMD (2020) [Multiple Sclerosis and Bladder Control Problems](#), accessed 14 October 2020

White, S., Kuper, H., Itimu-Phiri, A., Holm, R. and Biran, A. (2016) '[A qualitative study of barriers to accessing water, sanitation and hygiene for disabled people in Malawi](#)', *PLoS ONE*, 11(e0155043), accessed 14 October 2020

Wilbur, J. and Jones, H. (2014) '[Disability: Making CLTS Fully Inclusive](#)', *Frontiers of CLTS: Innovations and Insights* 3, Brighton: IDS, accessed 14 October 2020

Wilbur, J., Jones, H., Gosling, L., Groce, N. and Challenger, E. (2013) '[Undoing inequity: Inclusive water, sanitation and hygiene programmes that deliver for all in Uganda and Zambia](#)', in: 36th WEDC International Conference, Nakuru, Kenya, accessed 14 October 2020

Wood, L.N. and Anger, J.T. (2014) '[Urinary incontinence in women](#)', *The BMJ*, 349, accessed 14 October 2020

World Health Organisation (2018) '[10 facts on obstetric fistula](#)', *Fact File*, Geneva: WHO, accessed 14 October 2020

World Health Organisation (2011) [World Report on Disability 2011](#), Geneva: WHO, accessed 14 October 2020

World Vision and CBM Australia (2018) [Learning from Experience: Guidelines for Locally Sourced and Cost-Effective Strategies for Hygiene at Home for People with High Support Needs](#), World Vision and CBM Australia, accessed 14 October 2020

About the authors

Claire Rosato-Scott is a PhD Candidate at the University of Leeds, researching the provision of emergency sanitation for children with urinary incontinence.

Dr Dani Barrington is a Lecturer in the School of Population and Global Health at The University of Western Australia, whose research focuses on inclusive participatory methods that encourage people to talk openly about sensitive sanitation issues.

Dr Amita Bhakta is a freelance consultant with seven years' experience in working on equality, non discrimination and inclusion in WASH. Amita holds a PhD on the WASH needs of perimenopausal women making the transition to the menopause in urban Ghana.

Dr Sarah House is an Independent WASH Consultant / Public Health Engineer, committed to building WASH sector capacities on how to learn more effectively from communities, including from people who may be most disadvantaged, and turning that learning into action at scale.

Dr. Islay Mactaggart is an Assistant Professor in Disability & Global Health at the International Centre for Evidence in Disability (ICED) at the London School of Hygiene & Tropical Medicine (LSHTM).

With extensive experience of promoting equality and non-discrimination in water, sanitation and hygiene (WASH), **Jane Wilbur** works as a Researcher at the International Centre for Evidence in Disability at the LSHTM, focusing on disability and WASH.

About the series

This series provides practical, evidence-based guidance and recommendations on essential emerging issues and approaches to programming and learning. These publications are peer reviewed by sector experts from both academic and practice. The series is available both online and in hard copy in English, French and Portuguese. We welcome comments, ideas and suggestions, please contact us at slh@ids.ac.uk

All issues are available at: <https://sanitationlearninghub.org/series/frontiers-of-sanitation/>

Incontinence: We Need to Talk About Leaks

Incontinence is the involuntary leakage of urine or faeces. It is a global health, protection and social care challenge that has a significant impact on the quality of life of people that experience the condition, and those who care for people that do. The water, sanitation and hygiene sector can help provide support for people who live with incontinence to be able to live with dignity, but first we need to learn about the challenges people living with incontinence may be facing: we need to talk about leaks.



Institute of Development Studies at the
University of Sussex, Brighton BN1 9RE

Web <https://sanitationlearninghub.org/>

Email SLH@ids.ac.uk

Tel +44 (0)1273 606261

Fax +44 (0)1273 621202

 /SanLearningHub

 @SanLearningHub

 @SanLearningHub

IDS, a charitable company limited by guarantee: Registered Charity
No. 306371; Registered in England 877338; VAT No. GB 350 899914

Find out more

Subscribe to the SLH newsletter, share your experiences
and contribute to the SLH website by visiting
<https://sanitationlearninghub.org/connect-share-learn/>