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Summary guidance: Supporting people with incontinence in humanitarian and low- and middle-income contexts (LMICs)

Key messages

1. Incontinence is where **a person is not able to hold on to their urine or faeces** (‘the involuntary loss of urine or faeces’). It is a complex health and social issue. The effective containment of the leakage is essential for quality of life.
2. Leakage can happen at any time, day or night. **The level and severity of incontinence experienced varies** between people, and for each person can also vary day to day and over time. Incontinence **can lead to odours, skin infections, urinary tract infections and pressure sores, which can also be life-threatening.**
3. Some people experience incontinence due to being **born with a malfunctioning bladder and/or bowel**, but **many people can develop some form of incontinence**, including older people, women and adolescent girls who have given birth, women going through and after the menopause process, people with certain illnesses and/or disabilities, and people who are in highly stressful situations.
4. Incontinence can have a range of **emotional, social, practical and monetary impacts** for the person with incontinence and their carer(s). For example, it can affect their ability to earn an income, join community activities, go to school, receive services and socialise.
5. Incontinence is associated with a **high level of stigma** and causes much embarrassment. It can be challenging for people to admit to the condition, and to ask for help even if struggling to manage.

Sectors with responsibility for supporting people with incontinence

1. It is very important for **specialists working across sectors to coordinate** on supporting people with incontinence. Those which have key roles in supporting people with incontinence in low- and middle-income contexts include: Health including Midwifery and rehabilitation workers, WASH, Disability and Older Persons, Protection / GBV / Children / Gender, and Logistics.
2. Health care services should ideally be the **key service to support people with incontinence, but they may not always be equipped** to be able to provide this support. They may also not know what equipment and reusable products might be possible or useful.

Creating a supportive environment for people who live with incontinence

1. People with incontinence are likely to have **greater WASH needs**, including up to five times as much soap and water. They are also likely to need materials for capturing their urine or faeces and additional needs for containers for water collection and washing. **Privacy** is also very important to be able to manage their incontinence with dignity.
2. People may be shy to share information that they or a family member have incontinence and are struggling to manage it. **Different routes for building trust and reaching people** with incontinence and their carers will be needed. For example, by training community and hospital health workers, traditional birth attendants or community mobilisers on how to identify and communicate with people living with incontinence and their carers.

3. It is **very important to refer people** with incontinence who are immobile to health or disability specialists, because of the risk of urinary tract infections, or pressure sores, which can be life threatening. In some places however, professionals with these skills and knowledge may not exist.



Pressure sores

- *It is important to monitor the skin for any redness, swelling or skin breakages that could early signs 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 the position of the individual regularly.*

Urinary tract infections

- *A person who finds it difficult to communicate 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.*

Ref: No 3 - World Vision and CBM Australia (2018)

Useful resources on incontinence

1. Giles-Hansen, C (2015) *Hygiene needs of incontinence sufferers; How can water, sanitation and hygiene actors better address the needs of vulnerable people suffering from urine and / or faecal incontinence in low- and middle-income countries [online]*, WaterAid and SHARE Research Consortium.
<http://www.communityledtotalsanitation.org/resource/hygiene-needs-incontinence-sufferers>
2. 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. Pla Cordero, R. Cavill, S. House, S. (2016) 'Incompetent at incontinence - why are we ignoring the needs of incontinence sufferers? [online]' *Waterlines*, 35(3). <https://www.developmentbookshelf.com/doi/10.3362/1756-3488.2016.018>
3. 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 [online]*.
https://www.cbm.org.au/wp-content/uploads/2019/02/CBM_WV_hygiene-at-home.compressed.pdf
4. Continence product advisor website: <https://www.continenceproductadvisor.org/> - includes guidance and tips on products **currently available in high income** countries

Prepared by - This document has been compiled by members of an informal international cross-sectoral email group focused on learning how best to work with and support people with incontinence in humanitarian and low- and middle-income contexts.

Associated documents - This document is one of a set of four, being:

- a) Guidance; b) Summary guidance four-pager (this document); c) Case studies and d) References

Suggested citation - Rosato-Scott, C. Giles-Hansen, C. House, S. Wilbur, J. Macaulay, M. Barrington, D, J. Culmer, P, Bhakta, A. N and Burke, L (2019) 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>

Contact for further information - lmic-incontinence+owners@googlegroups.com

Creating a supportive environment for people to manage their incontinence: hygienically, safely, in privacy and with dignity

Including in humanitarian contexts

PHYSICAL NEEDS

Available incontinence materials and non-food items

Affordable, and culture, gender and age-appropriate; ongoing or continuous access (not one off). Items such as cloth / pads, soap, water containers, small bucket and lid, mattress protectors, rope, pegs (or catheters and other associated equipment with specialist support)

Private place(s) to change and bathe, and safe, hygienic and discrete methods to manage incontinence materials

Culture, gender and age-appropriate, safe, accessible and well-maintained water supply, sanitation and hygiene facilities

For changing materials and bathing

For washing and drying of materials and disposal

KNOWLEDGE AND ENVIRONMENT

Creating a supportive and safe environment

Breaking down stigmas and myths to enable people to acknowledge their incontinence and to ask for help

Information and dialogue on incontinence for women, men, girls and boys – including from health and disability specialists

On the daily management of the condition and the prevention of bed sores and urinary tract infections

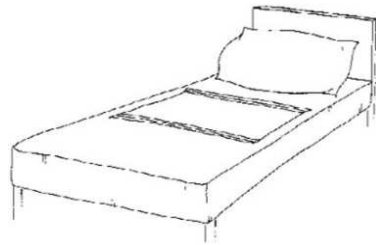
COMPETENT PROFESSIONALS AND COORDINATION

Key professionals recognise incontinence and are knowledgeable and confident

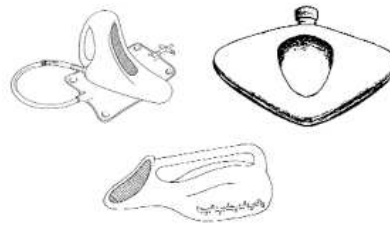
To advocate for support for people with incontinence, and to respond to incontinence needs

Cross-sectoral communication and action

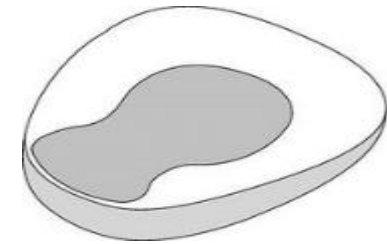
WASH, health and midwifery; disability and older persons; protection / GBV / children / gender; education; logistics / shelter / camp or community services



Mattress protector to stop liquids and fluids soaking into the mattress



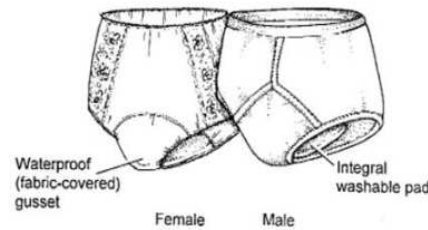
Hand-held urine containers



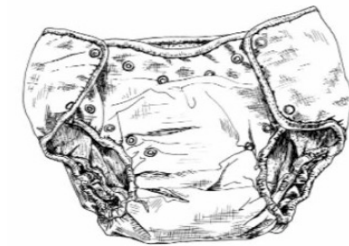
Bed pan



Commode chair



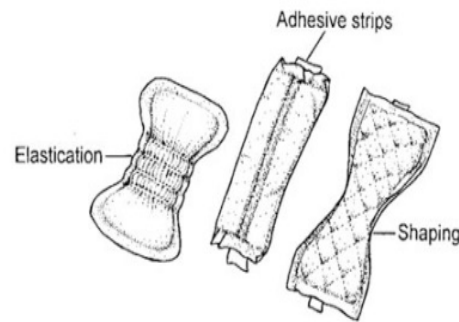
Re-usable female and male underwear



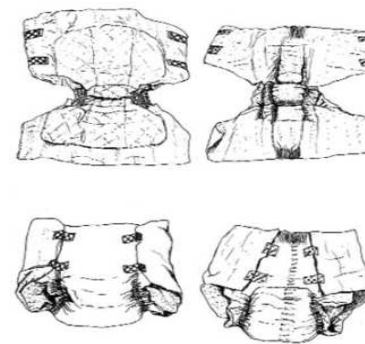
Re-usable adult or child diaper



Plastic pants



Disposable pads



Disposable incontinence pads (diapers)



Disposable pad with elasticated sides for holding in the fluids

Credit for images: Fader M, Cottenden A, Getliffe K, Gage H, Clarke-O'Neill S, Jamieson K, et al. (2018) Absorbent products for urinary/faecal incontinence: a comparative evaluation of key product designs. *Health Technology Assessment* 2008;12(29). Available at:

https://eprints.soton.ac.uk/189241/1/Absorbent_products_for_urinaryfaecal_incontinence.pdf; and the International Continence Society