

Hygiene needs of incontinence sufferers

HOW CAN WATER, SANIATION AND HYGIENE ACTORS BETTER
ADDRESS THE NEEDS OF VULNERABLE PEOPLE SUFFERING
FROM URINE AND/OR FAECAL INCONTINENCE IN LOW AND
MIDDLE INCOME COUNTRIES

September 2015
C Giles-Hansen

Acknowledgements

Funding for this study was provided by WaterAid. Special thanks to Sue Cavill and Sarah House for their guidance, support and valuable inputs.

The views expressed in this report do not necessarily reflect WaterAid's official policies. The author(s) are solely responsible for the content of this document.

Final version: 29 September 2015

Contact details

Chelsea Giles-Hansen
Independent Water, Sanitation & Hygiene (WASH) Consultant
Email: chelsea.gh@gmail.com
Skype: chelsea_gh

Table of Contents

List of tables and figures	3
1. Introduction	4
2. Background	4
a) What is incontinence?	4
b) Overview of prevalence	5
c) Living with and managing incontinence	6
3. Review of experiences and guidance on incontinence.....	9
4. How can WASH actors better address the hygiene needs of incontinence sufferers?	13
5. Recommendations	14
References	16
Annex A	17
Annex B	18

List of tables and figures

Figure 1: Prevalence of any urinary incontinence in women, by age group, data from 13 studies. Source: Minassian et al. 2003.	6
Figure 2: Median prevalence of stress, urge and mixed urinary incontinence, by age group. Source: Minassian et al. 2003.	6
Figure 3: Pictures of various disposable and reusable incontinence aids and products. Source: International Continence Society (ICS) 2013, unless otherwise stated.	8
Figure 4: Five WASH sector specific standards for age and disability inclusion, from Minimum Standards for Age and Disability Inclusion for Humanitarian Actions (2015).	10
Figure 5: Left: Wheelchair adapted for toilet use, with a small tyre inner tube in place of a seat and urine/faeces fall directly into the toilet hole (user remains seated). Middle: Locally bought and adapted metal commode chair with plastic pan (note the padded ring for comfort, wooden back support and waist belt for extra support). Right: Wooden commode chair for children (note the holes in sides to insert a wooden bar to prevent the child from falling forward).	11
Figure 6: Pictorial and written instructions for care of AFRIpads reusable cloth pads designed for menstrual hygiene. Source: AFRIpads website, afripads.com/our-products/use-and-care	12
Figure 7: Menstrual Rag Cleaning for Re-Use – part of the Assessment Tool developed under the USAID HIP in Uganda.	13

1. Introduction

Incontinence is a difficult and largely taboo subject, which to date has largely been overlooked by humanitarian agencies in relief/emergency settings and by agencies working in developmental settings. Humanitarian and development agencies often identify older or elderly persons, new or expectant mothers, children, and those with physical disabilities and/or learning difficulties, as being particularly vulnerable. These groups are vulnerable for a variety of reasons: physical or immunological susceptibility to communicable diseases, limited or impaired mobility, poor health status, may be prone to social exclusion, and so on.

Incontinence is just one of many conditions that affect a wide variety of people and particularly those in commonly identified 'vulnerable groups'. If not well managed, incontinence can mean significant implications for quality of life and personal dignity.

A substantial amount of urinary and faecal incontinence related research exists, mainly from hospital (or clinical) and elderly rest-home (or care-facility) settings. However, there remains a lack of evidence-based guidance for humanitarian and developmental actors (particularly those providing water, sanitation and hygiene (WASH) and/or health services) on how best to support the needs of urinary and/or faecal incontinence sufferers in resource-scarce settings.

Further, the newly adopted Sustainable Development Goals¹ (SDGs) have a strong focus on achieving universal access to health services and reduction of inequalities. Goal 3 (Ensure healthy lives and promote well-being for all at all ages) and Goal 10 (Reduce inequalities within and among countries) are particularly relevant. Humanitarian and development actors working in WASH and health must pay attention to the needs of disadvantaged or marginalised people, including those living with urinary and/or faecal incontinence. WASH and health interventions need to be designed and implemented inclusively, with consideration of the needs of those who live with incontinence.

This note reviews the documented experiences and current guidance around supporting those with urinary and/or faecal incontinence in a humanitarian and/or development setting. For the remainder of this document, the term incontinence will refer to urinary and/or faecal incontinence (unless specified). This note provides an overview of incontinence, gives information about how people generally manage their incontinence, and outlines experiences and resources that may be useful.

Recommendations including further research to explore the hygiene needs of incontinence sufferers in groups that are commonly identified as vulnerable by humanitarian and development agencies, and development of practical resources for WASH and health practitioners are outlined. It is hoped that this note provides a basis for further, more detailed studies around incontinence in humanitarian and development settings.

2. Background

a) What is incontinence?

Incontinence is a complex health and social issue faced by many in developing and developed countries alike. Incontinence can cause devastating social and economic exclusion, debility, and psychological stress (Amin et al. 2008).

Incontinence can be classified as faecal, urine, or both. Urinary incontinence is defined as the involuntary loss of urine that is objectively demonstrable and is a social or hygienic problem (Ali et

¹ www.un.org/sustainabledevelopment/sustainable-development-goals/

al. 2013). Faecal, or bowel, incontinence is an inability to control bowel movements, resulting in the involuntary passage of stools (NHS 2013).

Incontinence can affect:

- Elderly or older people
- Men, women and children with physical disabilities and/or learning difficulties
- Women and adolescent girls who have recently given birth
- Women and adolescent girls with fistula from prolonged and/or obstructed childbirth
- People who have had certain types of illness (e.g. stroke) or operation (e.g. such as removal of prostate)
- Stress or urge incontinence (see below) can also affect both men and women of all ages across their lifetime due to malfunctioning bladder and urinary systems

b) Overview of prevalence

The International Continence Society (ICS) estimates that incontinence affects 1 in 4 women over the age of 35 years, and 1 in 10 adult men. In a meta-study from 2003, the median prevalence of female urinary incontinence globally was found to be 27.6% (Figure 1), with prevalence of significant incontinence increasing with age (Minassian 2003). This meta-study included data from population-based studies in 35 countries, however only 1 was from Africa (Nigeria) and very few studies from low or middle income countries were included (Nigeria, Thailand, Turkey²). The majority of the 35 studies were from high income countries in Europe, North America and Australasia.

Risk factors for incontinence included parity (number of times a woman has given birth), obesity, chronic cough, depression, poor health, lower urinary tract symptoms, previous hysterectomy, and stroke. It is important to note that there are large variations in the severity, type and impacts of incontinence.

The most common cause of urinary incontinence reported in the meta-study was stress (50%), then mixed (32%) and then urge (14%) (Figure 2). Stress incontinence is the involuntary leakage of urine when the bladder is under pressure (for example when coughing, laughing or during exercise), and urge incontinence is the involuntary leakage of urine during or soon after a sudden, intense urge to pass urine (NHS 2014). Mixed incontinence is a combination of both stress and urge incontinence.

No additional data or estimates were found for incontinence in low and middle income countries, making it very difficult to understand the extent and burden of incontinence in these contexts. The prevalence of incontinence in low and middle income countries could be higher than the global estimates outlined above for a number of reasons, including poor access to health services and care (e.g. higher prevalence of long and obstructed labour, limited ante- and post-natal care for mothers, sexual and reproductive diseases which go un-detected and un-treated, lack of access to surgery for existing conditions etc.), and higher rates of chronic illnesses such as HIV/AIDS.

² Classification of low, middle and high income countries is dependent on the classification scheme used (e.g. World Bank or other).

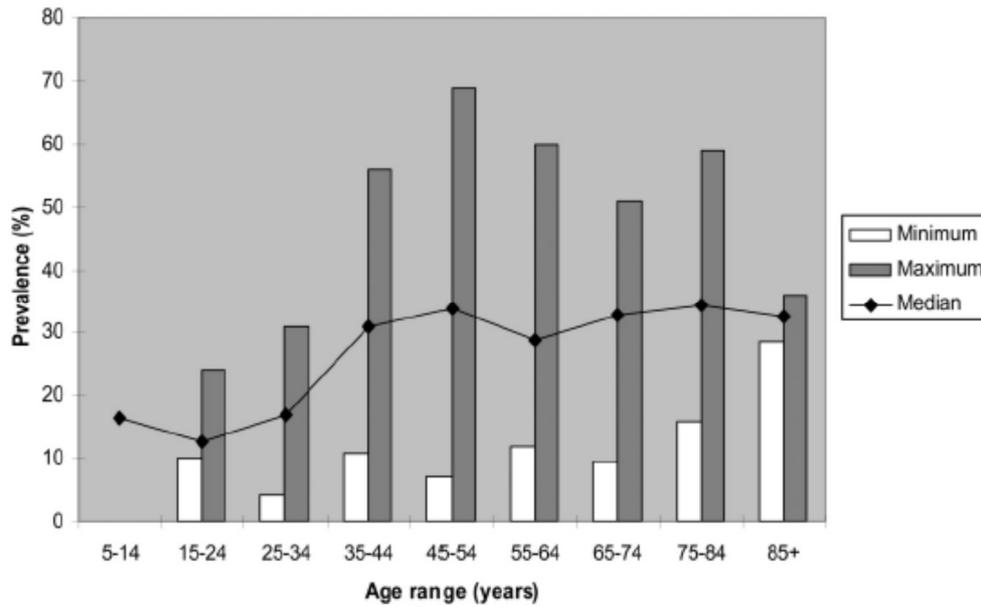


Figure 1: Prevalence of any urinary incontinence in women, by age group, data from 13 studies. Source: Minassian et al. 2003.

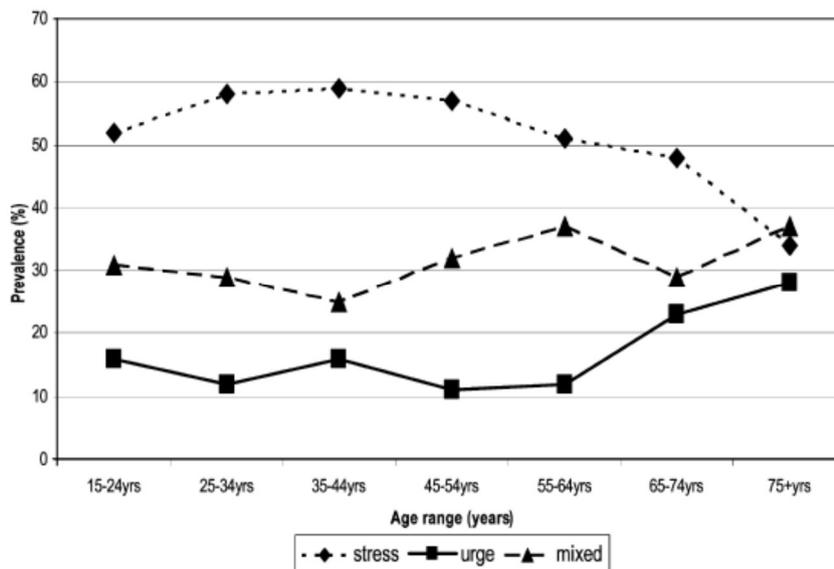


Figure 2: Median prevalence of stress, urge and mixed urinary incontinence, by age group. Source: Minassian et al. 2003.

c) Living with and managing incontinence

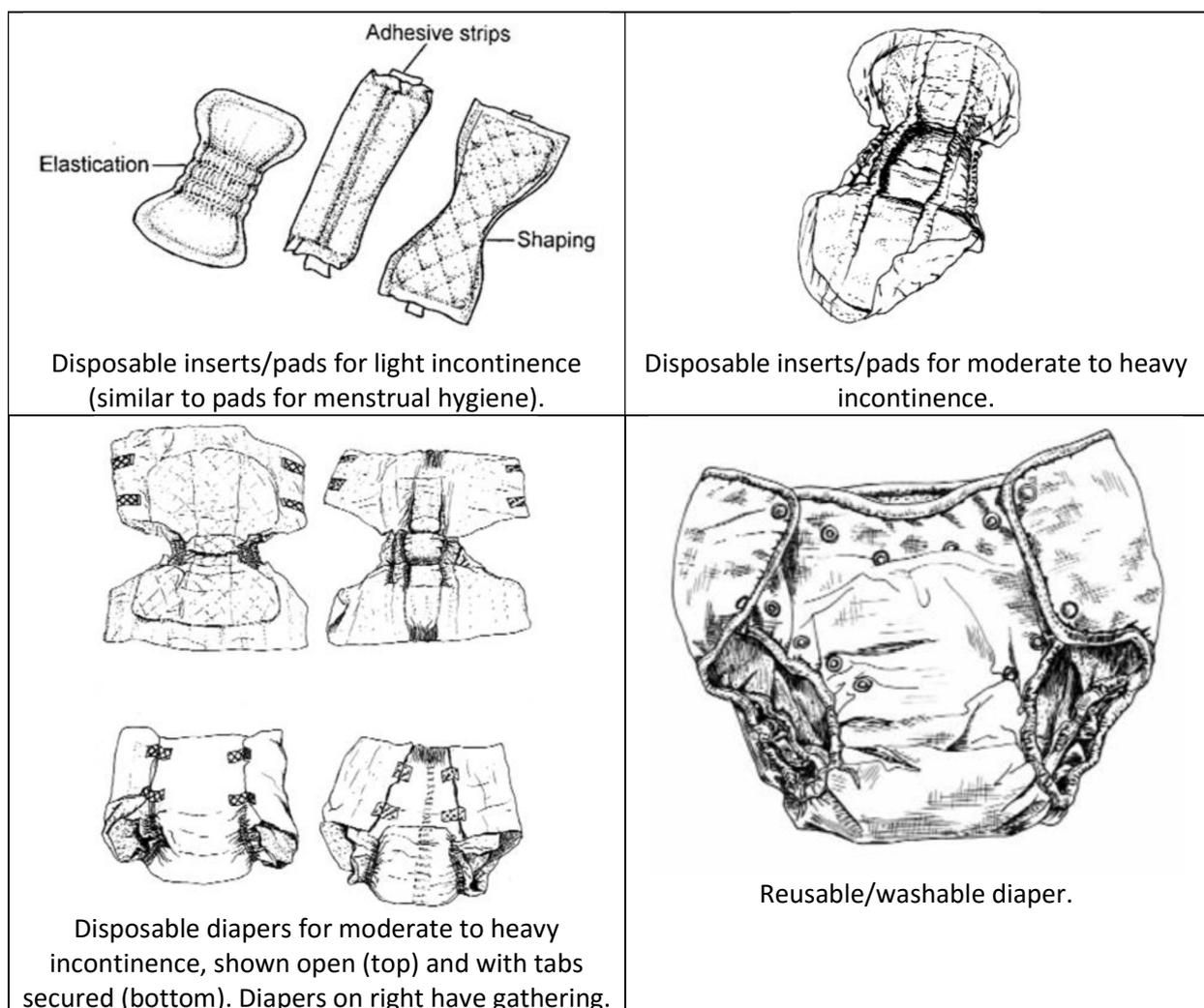
Many people living with incontinence suffer embarrassment and fear of leakage or smell. They may be ostracised, isolated or teased (due to their condition or the related smell). As well as being anxious about finding a place (sometimes at very short notice) to urinate and/or defecate, people living with incontinence may be concerned with how to protect themselves from leaking urine and/or faeces, how to clean themselves discretely and how to dispose of any materials they may have used to soak up the urine and/or faeces. All of these factors can have severe negative impacts on day-to-day activities, everyday life and personal confidence and dignity.

For stress incontinence (urine), pelvic floor muscle exercises may help to control the incontinence. For other types of incontinence, medication may help, or the incontinence may reduce in severity over time (e.g. between 6 and 12 months after a prostate operation, or in the weeks or months following childbirth). For both urinary and faecal incontinence, surgery may also be an option available to treat or reduce the severity of the incontinence. Obstetric fistula leaves women with often severe urine and/or faecal leakage³ and can only be repaired through surgery.

In most high-income countries, a wide variety of support for urinary and faecal incontinence is available through family health clinics, national health services, and national in/continence associations.

A large amount of information, resources and support is available online through websites (for example; www.continence.org.nz, www.canadiancontinence.ca, www.continence.org.au). Information and products specifically targeted to men are also common (for example, www.dryfella.co.nz).

Incontinence products and aids (as shown in Figure 3 below) are generally available in supermarkets, pharmacies or more specialised health stores in high income countries. In low and middle countries however, these supply chains and mechanisms for incontinence products and aids may not be available or may only reach larger centralised cities.



³ www.fistulafoundation.org/what-is-fistula/

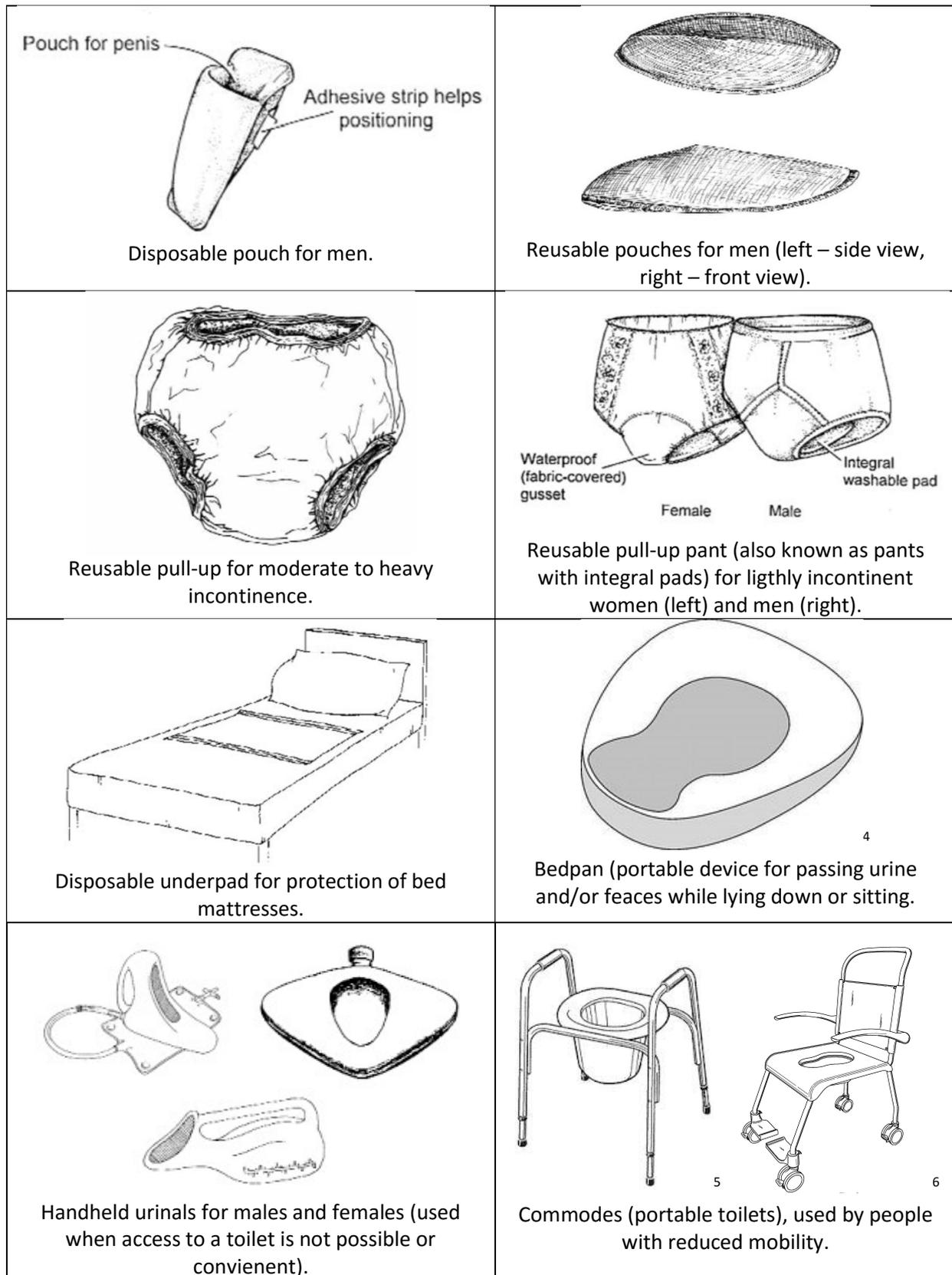


Figure 3: Pictures of various disposable and reusable incontinence aids and products. Source: International Continence Society (ICS) 2013, unless otherwise stated.

⁴ Source: www.fotosearch.com/illustration/urinating.html

⁵ Source: www.ahrq.gov/professionals/systems/long-term-care/resources/injuries/fallspix/fallspixmanapd.html

⁶ Source: www.google.com/patents/USD679513

Incontinence places a large economic burden on society (ICS 2005). The annual direct cost of urinary incontinence in the United States (in 1995 dollars) was estimated as \$16.3 billion, including \$12.4 billion (76%) for women and \$3.8 billion (24%) for men (Wilson et al. 2001).

Patients often incur sizeable costs when paying for lost wages, routine care products (e.g. purchase of absorbent pads, underwear etc.), treatments and long-term care (ICS 2005). It is estimated that for female urinary incontinence in the United States, between 50% - 75% of the cost of incontinence is attributed to routine care, including purchase of absorbent pads, protection and laundry costs (e.g. soap, water, electricity). Routine care costs are reported to vary widely from \$50 USD to \$1000 USD per person per year (Leslee et al. 2006). Costs also vary widely by country – and in some country government health insurance covers routine care products (e.g. Sweden) while in others low-income patients are eligible for a subsidy (e.g. Australia) (ICS 2005).

No information was found on costs related to incontinence in low or middle income countries. In these contexts, people suffering from incontinence may not have access to products (e.g. not stocked in markets or pharmacies) or the financial means to purchase sanitary protection materials/cloths/mattresses, or extra soap and water, in order to be able to manage their incontinence (or care for a family member who has incontinence). Severe incontinence may prevent people from being able to work, or not being able to generate or contribute towards a livelihood for their family. They may be a burden on their family when means and finances are already stretched. In emergency contexts, incontinence (similarly to menstruation in some places), may restrict people's ability to access food and water distributions, and others may be unwilling to assist them due to smell or stigmatism⁷.

3. Review of experiences and guidance on incontinence

A desk-based review of resources, experiences and guidance documents related to incontinence was conducted, within the humanitarian and development sectors. Clinical or 'high income/developed country setting' resources were not included.

Very limited information and guidance relating to incontinence was found. The desk review returned a total of three resources which specifically mention incontinence:

- i. In 2005, Christian Blind Mission (CBM) International⁸ conducted a review of disability in the Tsunami Emergency Response in South-East Asia. Minor but specific references to incontinence are included, with recommendations including provision of additional quantities of bathing and laundry soap, and changes of clothing and bedding, to those people with incontinence problems.
- ii. The SPHERE Handbook is a widely used reference and resource for humanitarian and development actors. Older people, persons living with disability and gender are all cross-cutting themes incorporated into the core standard and technical standards (including WASH). In the 2011 version of the SPHERE Handbook, there are two minor references to vulnerable people with incontinence (pages 95 and 272), however no detailed information or practical guidance as to how to provide support.
- iii. In August 2015, the Minimum Standards for Age and Disability Inclusion in Humanitarian Action (pilot version) were launched as part of the Age and Disability Capacity Building Programme

⁷ Personal communication, response for South Sudanese refugees in Gambella (Ethiopia).

⁸ hpod.org/pdf/looking-with-disability-lens.pdf

(ADCAP) on behalf of the Age and Disability Consortium⁹. The ADCAP aims to strengthen the capacity of humanitarian agencies to deliver age and disability inclusive activities in emergency response. As well as Key Inclusion Standards, there are Sector Specific Standards related to particular themes – one of which is water, sanitation and hygiene (WASH). Other sectors with specific standards include Protection, Food security and livelihoods, Nutrition, Shelter and Non-food items (NFIs), Health and Emergency Education.

The 5 WASH sector specific Standards from the Minimum Standards for Age and Disability Inclusion in Humanitarian Action are shown below. For each of the 5 standards, specific actions have been elaborated to enable humanitarian actors to meet each standard. Related specifically to incontinence, an action under WASH standard 2 is “Inform those with specific WASH needs (e.g. incontinence) and their carers about the hygiene items, services and facilities that can be provided (including any additional or specialised items or facilities that may be needed).”

Another action under WASH standard 5 is “Distribute additional hygiene products to people with disabilities and older people if required. Train assessment teams and WASH staff to consult in gender-sensitive ways with people with disabilities and older people about specific hygiene needs (and with carers where necessary). Ensure that those with specific needs (e.g. incontinence) have easy access to additional hygiene products and intimate hygiene items according to their needs. “

WASH STANDARD 1:

People with disabilities and older people, and their carers, are fully included in the design, implementation, monitoring and evaluation of WASH services and facilities, and they participate in relevant needs assessments.

WASH STANDARD 2:

Information on WASH services and facilities is fully accessible and available to people with disabilities and older people, and their carers.

WASH STANDARD 3:

People with disabilities and older people, and their carers, have full access to an adequate supply of water for drinking, cooking and other domestic use.

WASH STANDARD 4:

People with disabilities and older people have full access to latrine facilities that are appropriate for them to use safely and with dignity.

WASH STANDARD 5:

People with disabilities and older people, and their carers, have full access to hygiene services including an adequate and appropriate supply of hygiene items, and to hygiene facilities that are appropriate for them to use safely and with dignity.

Figure 4: Five WASH sector specific standards for age and disability inclusion, from Minimum Standards for Age and Disability Inclusion for Humanitarian Actions (2015).

Under the Shelter, Settlements and NFI’s sector specific Standard 4, an action to meet the standard is: “Using community or outreach services, identify those with specific needs and the most vulnerable (e.g. older people with frailty and those with multiple disabilities or incontinence) and their carers. Ensure that their needs are met, e.g. requirements for extra blankets in cold and wet weather, mattresses, additional clothing or underwear, appropriate footwear, additional sanitary or hygiene materials (such as incontinence pads or catheter bags) and special utensils for eating and drinking.”

⁹ Consortium of seven agencies: CBM, DisasterReady.org, Handicap International, HelpAge International, IFRC, Oxford Brookes University and RedR UK.

Despite not specifically mentioning incontinence, a number of resources were found to be relevant and potentially useful:

- i. Handicap International developed a Disability Inclusion Checklist for Emergency Contexts¹⁰ in 2013, which outlines principles for the protection and inclusion of those with disabilities and injuries across different sectors including WASH, health, nutrition, rehabilitation and housing, livelihoods and education. The checklist is a succinct, clear and valuable tool for humanitarian staff in WASH and other sectors, to enable improved inclusion and better programming and support for vulnerable people. However, there is no explicit mention of incontinence in the checklist.
- ii. The Water, Engineering and Development Centre's¹¹ Water and Sanitation for Disabled People and other Vulnerable Groups is a very detailed and practical resource with many useful suggestions and advice for supporting personal hygiene, transporting water, washing and toileting aids for people who are physically impaired or challenged. Three examples of adapted toileting aids (from Bangladesh) are shown in Figure 5.



Figure 5: Left: Wheelchair adapted for toilet use, with a small tyre inner tube in place of a seat and urine/faeces fall directly into the toilet hole (user remains seated). Middle: Locally bought and adapted metal commode chair with plastic pan (note the padded ring for comfort, wooden back support and waist belt for extra support). Right: Wooden commode chair for children (note the holes in sides to insert a wooden bar to prevent the child from falling forward). Source: WEDC 2006.

- iii. There are numerous briefing notes, guidelines and resources developed for humanitarian and development agency staff around water, sanitation and hygiene (WASH) and vulnerable groups such as those with disabilities, and older and elderly persons (such as the Inclusive WASH portal and resources¹² led by WaterAid Australia in collaboration with The WASH Reference Group, WEDC's briefing note on WASH and Disability¹³, and HelpAge International/UNHCR's 'Older people in disaster and humanitarian crises: Guidelines for best practice'). However, none of these resources specifically mention incontinence as an important yet manageable health issue, or provide any guidance on how to support those with incontinence.

Additionally, several national health departments and continence associations have translated information and education resource materials into other languages (to make information more accessible to immigrants, refugees and asylum seekers). For example, the Australian Department of

¹⁰ Source: www.handicap-international.de/fileadmin/redaktion/pdf/disability_checklist_booklet_01.pdf

¹¹ Water, Engineering and Development Centre at Loughborough University: wedc.lboro.ac.uk/about/about.html

¹² www.inclusivewash.org.au/

¹³ wedc-knowledge.lboro.ac.uk/collections/equity-inclusion/disability-wash.html

Social Services has translated bladder health and incontinence information brochures into numerous languages, including Arabic, Dinka, Somali, Tagalog and Vietnamese¹⁴.

Resources and experiences from other programmes (not specifically incontinence related) could be adapted and may provide useful learning and guidance for WASH practitioners around incontinence.

- i. Menstrual hygiene management (MHM) is an area where various similarities can be drawn with incontinence. For example, many women use reusable sanitary pads and cloths to absorb their menstrual flow, which are then washed and dried before reuse. It could be assumed that a similar process would be suitable for cloth or reusable pads that are used for incontinence (with some adaptations to account for the different nature of urine and/or faeces from incontinence compared to menstrual blood). Existing guidance and resources (such as from AFRIpads who produce reusable sanitary pads in Uganda, example shown in Figure 6 or full care instructions here: water.care2share.wikispaces.net/file/view/Afripads+job+aid+copy.pdf) could be adapted to the washing and drying of reusable incontinence products.



Figure 6: Pictorial and written instructions for care of AFRIpads reusable cloth pads designed for menstrual hygiene. Source: AFRIpads website, afripads.com/our-products/use-and-care.

- ii. The USAID Hygiene Improvement Project (HIP) developed a number of tools and resources to support the integration of WASH into HIV/AIDS home-based care programming. Simple instructions for making low-cost plastic pants were developed as part of the project¹⁵. Plastic pants are designed for incontinence, to protect bedding and clothing from urine and faeces. These can be made locally with plastic sheeting and minimal input from a tailor (or similar). It is important that cotton cloth is always placed in between skin and the plastic.

Simple resources that are pictorially based, and aimed at use by caregivers with low literacy levels could be adapted to WASH or health practitioners for assessment of incontinence related hygiene practices (e.g. washing and drying cloth used to absorb urine and/or faecal leakage). An example of a simple assessment tool developed for caregivers around washing menstrual rags in Uganda is shown in Figure 7.

¹⁴ www.bladderbowel.gov.au/footer/publications/factsheets.htm#

¹⁵ water.care2share.wikispaces.net/file/view/USAID+HIP+et+al+-+CC+-+Plastic+pants+copy.pdf

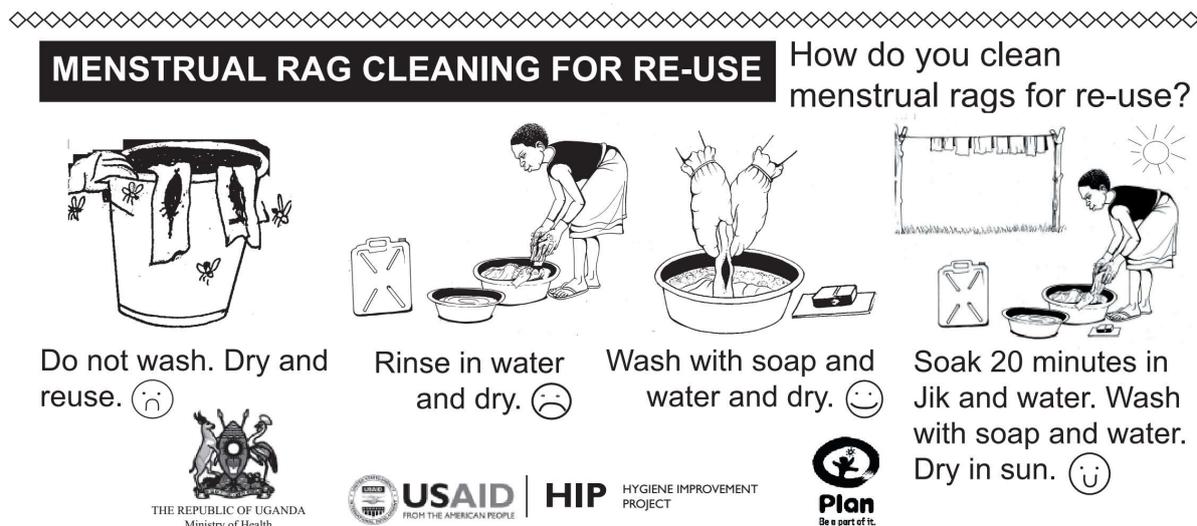


Figure 7: Menstrual Rag Cleaning for Re-Use – part of the Assessment Tool developed under the USAID HIP in Uganda.

Case study: Adult diapers – a necessary but neglected hygiene item in humanitarian responses?

In January 2013, the Seychelles were hit by a tropical cyclone causing damage, flooding and displacement of 250 families. The Seychelles Red Cross Society, supported by the IFRC, responded to the emergency including hygiene and health promotion, vector control, and non-food item distributions.

An evaluation of the overall response was conducted in June 2013, including a beneficiary satisfaction survey. Target beneficiaries received appropriate hygiene and menstrual hygiene items, either through direct distributions or vouchers.

However, the evaluation team interviewed a household where an adult man lived with his brother who had learning disabilities. Although they had received support following the cyclone and were grateful for this, the man specifically mentioned that the one most important thing he had needed in the weeks following the cyclone were adult nappies for his brother, who suffers from incontinence.

4. How can WASH actors better address the hygiene needs of incontinence sufferers?

Although incontinence-specific guidance for WASH staff to better support people living with incontinence is limited, the Minimum Standards for Age and Disability Inclusion, inclusion checklists and guidelines provide many practical and straightforward actions.

To better address the hygiene needs of incontinence sufferers, WASH actors can¹⁶:

- Talk to people about their WASH needs: Find culturally appropriate and sensitive methods for assessment and identification of those who may suffer from incontinence. Assessments can be

¹⁶ Based on guidance in Module 7 of the Menstrual Hygiene Matters resource, “Supporting women and girls in vulnerable, marginalised or special circumstances”.

based on existing formats and incorporate guidance from the Minimum Standards and Inclusion Checklist (outlined above), with consultation and questions explicitly for incontinence added in. It is critical to ensure that inclusive and sensitive needs assessments are conducted, where older people, those with physical disabilities and learning difficulties (or their carers), new mothers, women with fistula or child-birth related conditions, and those with chronic illnesses or injuries are consulted on their water, sanitation and hygiene needs. These vulnerable groups should participate in assessment, planning, implementation and evaluation of WASH activities.

- Offer a range of options of protection materials and incontinence aids – for lesser and more severe incontinence, and for urinary versus faecal incontinence: Be sure to understand the type of hygiene and personal protection items that incontinence sufferers prefer and will use (e.g. disposal or washable cloth, sanitary pads, absorbent underwear, adult diapers etc.), as well as their management (e.g. washing, drying, disposal) of these materials. Locally built incontinence aids such as commodes (close to people sleeping areas which can be emptied), wheelchairs with toileting holes, or bedpans should be considered.
- Incontinence sufferers may need additional personal protection items (e.g. cloth or sanitary materials such as pads), additional hygiene items such as soap and water, as well as bedding or clothes. Sanitation and water facilities should be safe and accessible (e.g. reasonable distances to water sources, sufficiently large latrine superstructure with hand-rails and ramp, private drying and washing area etc.).
- Train women and girls to make their own sanitary materials that are also suitable for their incontinence (or the incontinence of family members or others who they may care for).
- WASH actors should advocate for the hygiene and sanitation needs of incontinence sufferers both internally and externally.
- Collaboration and working together with other sectors is important to ensure universal access and that marginalised and vulnerable populations are not left behind. In particular, the WASH sector should engage with actors who work with elderly populations (at home or in a care facility e.g. home for elderly run by a local NGO), those with physical disabilities and/or learning difficulties (or their carers), birthing/reproductive health clinics and fistula hospitals or care facilities.

5. Recommendations

- i) Further research should be conducted to understand urinary and faecal incontinence, its impact on daily life, and the availability and preferences for protection material and hygiene items of incontinence sufferers in low and middle income countries. Qualitative data could be collected from interviews with:
 - a. People living with incontinence (and/or their carers),
 - b. Relevant staff from humanitarian organisations (particularly WASH or health staff) with experience in supporting vulnerable groups and/or incontinence sufferers.

Humanitarian and development organisations commonly distinguish between and identify different vulnerable groups in acute, recovery and long-term programming. Ideally data should be gathered from across the different groups (older or elderly persons, new and expectant mothers, women with fistula, and people with physical disabilities and/or learning difficulties), in order to explore the different characteristics (if any) of incontinence sufferers and the range of incontinence issues they experience and particular hygiene challenges.

Example semi-structured and narrative interview guides have been developed and are included in Annex A and B. These could be used as a guide or basis for adaptation, and have not been field tested.

- ii) Guidelines and tips for conducting inclusive and sensitive needs assessment (firstly, to identify those with urinary/faecal incontinence; and secondly, how to determine their needs) should be developed. Questions specifically for incontinence should be added onto existing assessment tools and inclusion checklists.
- iii) Document case studies and experiences to better provide support to those who suffer from urinary and/or faecal incontinence, for information sharing with humanitarian and developmental agencies. In particular, experiences on the type and management (e.g. washing/drying/disposal) of hygiene and personal protection items that people with incontinence need should be included.
- iv) WASH actors should utilise existing resources (such as the Minimum Standards and Inclusion Checklists), and trial them in field-based responses and programmes which include support to people with urinary and/or faecal incontinence. Feedback can be provided on relevance and usefulness of these existing resources, and whether a WASH specific resource would be beneficial.
- v) Encourage the continued inclusion of references about and guidance for incontinence-related activities and support into hygiene promotion and WASH resources (including hygiene and dignity kit case studies and resources).
- vi) Sensitise WASH and health staff to the issue of urine and faecal incontinence, and build their confidence and capacity to address incontinence in activities and programmes.
- vii) Strengthen monitoring of the inclusion of and support to vulnerable people (including those who suffer from incontinence) in WASH activities and interventions, to enable tracking of progress towards ensuring universal access.

References

- Ali H.S., Lakhani N.A., Sarwar N.G. 2013. Urinary incontinence three months after delivery; prevalence and risk factors. *Professional Med Journal* 2013; 20(4): pgs 530-536.
- Amin E.B., Nojomi M., Rad R.B. 2008. Urinary incontinence: hospital-based prevalence and risk factors. *Journal of Research in Medical Sciences* January & February 2008; Vol 13, No 1.
- Cavill S., House S., Mahon T., 2012. Menstrual hygiene matters: A resource for improving menstrual hygiene around the world, WaterAid and SHARE Research Consortium. Available at: www.wateraid.org/what-we-do/our-approach/research-and-publications/view-publication?id=02309d73-8e41-4d04-b2ef-6641f6616a4f [Accessed: 26 August 2015]
- International Continence Society (ICS) 2005. Economics of Incontinence: Chapter 2, Committee 24. Available at: www.ics.org/Publications/ICI_3/v1.pdf/chap2.pdf [Accessed: 26 August 2015]
- Jones H.E. & Reed R.A 2005. Water and Sanitation for Disabled People and Other Vulnerable Groups – Designing services to improve accessibility. Water, Engineering and Development Centre, Loughborough University, United Kingdom.
- Leslee L.S. et al. 2006. The “Costs” of Urinary Incontinence for Women. *International Journal of Gynaecology and Obstetrics* 107 2006 908-916. Available at: www.ncbi.nlm.nih.gov/pmc/articles/PMC1557394/ [Accessed: 26 August 2015]
- Minimum Standards for Age and Disability Inclusion in Humanitarian Action (2015). Age and Disability Capacity Building Programme (ADCAP), the Age and Disability Consortium. Available at: www.cbm.org/article/downloads/54741/Minimum_Standards_for_Age_and_Disability_Inclusion_in_Humanitarian_Action.pdf [Accessed: 26 August 2015]
- Minassian V.A., Drutz H.P., Al-Badr A. 2003. Urinary incontinence as a worldwide problem. *International Journal of Gynaecology and Obstetrics* 82 (2003) 327–338. Available at: [www.ijgo.org/article/S0020-7292\(03\)00220-0/pdf](http://www.ijgo.org/article/S0020-7292(03)00220-0/pdf) [Accessed: 30 April 2015]
- National Health Services 2013. Bowel Incontinence [Online]. United Kingdom. Available at: www.nhs.uk/conditions/Incontinence-bowel/Pages/Introduction.aspx [Accessed:27 October 2014]
- National Health Services 2014. Urinary Incontinence [Online]. United Kingdom. Available at: www.nhs.uk/conditions/Incontinence-urinary/Pages/Introduction.aspx [Accessed:15 February 2015]
- Oosters, B. 2005. Looking with a disability lens at the disaster caused by the Tsunami in South-East Asia, Disability-Tsunami Emergency Response for ACFID, Christian Blink Mission (CBM) International. Available at: <http://hpod.org/pdf/looking-with-disability-lens.pdf> [Accessed: 27 October 2015]
- SPHERE Project, 2011. The SPHERE Handbook: Humanitarian Charter and Minimum Standards in Humanitarian Response, 2011 Edition, SPHERE Project (consortium of NGO’s and the Red Cross Red Crescent Movement). Available at: www.sphereproject.org/handbook/ [Accessed: 15 February 2015]
- USAID/Hygiene Improvement Project, Plan International, Uganda Water and Sanitation NGO Network, Ministry of Health, Republic of Uganda (2008), Uganda HIV and WASH Integration Kit. Available at: www.hip.fhi360.org/page/4489.html
- Wilson L., Brown J.S., Shin G.P., Luc K.O., Subak L.L. 2001. Annual direct cost of urinary incontinence. *International Journal of Gynaecology and Obstetrics* 98 (2001) 398-406. Available at: <http://www.ncbi.nlm.nih.gov/pubmed/11530119> [Accessed: 18 September 2015]

Annex A

SAMPLE SEMI-STRUCTURED INTERVIEW GUIDE – INCONTINENCE SUFFERERS

Part A: INTRODUCTION

A1. *What does 'incontinence' mean to you?*

(Interviewer will need to translate the concept of 'incontinence' = involuntary leakage of urine/faeces.

Probe: Let the interviewee explain what they understand incontinence to be.

Part B: EXPERIENCES OF LIVING WITH INCONTINENCE

B1. *Can you tell me about your experiences of living with incontinence?*

Probe: How often do you leak urine/faeces? Do you get any different feeling or warning before it happens? Does any activity trigger your incontinence? Severity? [Try to understand what type and severity of incontinence the interviewee suffers from].

Probe: When did your incontinence start? Do you know what the cause is?

B2. *In your everyday life, how do you deal with (or manage) your incontinence?*

Probe: Can you describe the items/products you use to try and maintain personal hygiene?

- Cost or access to items/products
- Washing and drying – where, how

Probe: Do you ever feel embarrassed or afraid? How do you cope with this?

Part C: CHALLENGES

C1. *What are the main challenges that you face in managing your incontinence?*

Probe: Get the interviewee to describe and rank the difficulties (challenges) they face (many of which will have been brought out in Part B).

Part D: SUPPORT AND ASSISTANCE

D1. *Can you tell me about the support or assistance you have had for your incontinence?*

Probe: Who did you tell about your problem or ask for help? [Friends, family, community, professional]

Probe: Did you visit a health clinic or nurse to ask for assistance/treatment?

Probe: Ask them to distinguish between physical and psychosocial support

Probe: Ask them to describe their experiences and the way they felt when seeking help, if at all

Probe: Does this support/assistance meet your needs?

Probe: Does your incontinence affect your ability to be independent? How does this make you feel?

D2. *What type of assistance or support would you like to receive to help you manage your incontinence?*

Probe: Take them through the needs identified above and ask them to give suggestions that may help to meet their needs

Probe: Who would you want to provide help/assistance? Why?

Part E: EMERGENCY OR DISASTER EXPERIENCES

E1. *Have you ever been affected by a major life-changing event, such as a natural disaster or emergency? (Give examples) If No – move to Part F. If Yes – continue.*

Probe: Ask the interviewee to describe how the event affected their life, and in particular how it affected them being able to manage their incontinence on a daily basis

Probe: Did they receive any assistance from humanitarian agencies or Government? What did they receive? Did this meet their needs? What support would they have liked to receive?

Part F: END

Thank you for your time. Do you have any questions that you would like to ask me?

Annex B

**SAMPLE INTERVIEW GUIDE (NARRATIVE (OR QUALITATIVE) INTERVIEW) –
WASH / AGENCY STAFF**

- a) Which ‘vulnerable groups’ does your agency typically support in emergencies?
- b) How does your agency support these groups/What type of support is provided (specific to each group or generally)
- c) Do you assess whether these groups have needs around incontinence?
- d) Has your agency or partners ever worked specifically with urinary/faecal incontinence sufferers?
- e) Do you know of any reviews, evaluations or guidance documents within the WASH or other sector that provide specific guidance on incontinence, particularly in vulnerable groups (aged or elderly, physically disabled and/or learning difficulties, new or expectant mothers)?
- f) Do you think incontinence is an issue that the WASH sector should worry about? Why or why not? What about other sectors?
- g) What do you think are the main challenges that WASH staff face in supporting those with incontinence?
- h) What do you think are the main challenges that WASH agencies face in supporting those with incontinence?
- i) What could WASH staff and agencies do to better identify and support urinary/faecal incontinence sufferers in emergencies and development settings?
 - What kinds of partnerships or collaborations with other sectors could support this?