Taking Stock: Incompetent at incontinence – why are we ignoring the needs of incontinence sufferers?

BENEDICTE HAFSKJOLD, BISERKA POP-STEFANIJA, CHELSEA GILES-HANSEN, ERIC WEERTS, ERIN FLYNN, JANE WILBUR, KATE BROGAN, KWEKU ACKOM, MICHELLE FARRINGTON, MINJA PEUSCHEL, NICOLE KLAESENER-METZNER, RICARDO PLA CORDERO, SUE CAVILL, and SARAH HOUSE

HOW WOULD YOU COPE if you had no control over how you urinated or defecated and regularly or constantly leaked urine or faeces? How would this make you feel? How would you deal with the smell, with the indignity? What if you were a young teenager, traumatized by very stressful events and returned to bed-wetting as a result? And what would you do if you didn't have the money to buy spare underwear or incontinence protection products or those are simply not available to you? Could you manage if you were suddenly displaced in an emergency and did not have access to a toilet, shower or bathing facilities, or your usual materials and coping mechanisms? What if you lived in a camp and your toilet or bathing shelter was a 5 minute walk away and had a long line in front of it? Would you be able to stand in line at food distribution or water collection points, go to school, or look for or undertake work?

Benedicte Hafskjold (bha@nca.org) is WASH Advisor at Norwegian Church Aid; Biserka Pop-Stefanija (bpop_stefanija@yahoo.com) as an Independent; Chelsea Giles-Hansen (chelsea.gh@gmail.com) is an independent WASH consultant; Eric Weerts (eric.weerts@handicap.be) is DRT - Technical Referent Emergency and Rehabilitation at Handicap International; Erin Flynn (ErinFlynn@wateraid.org) is Research Manager, WaterAid; Jane Wilbur (janewilbur@wateraid.org) is Equity, Inclusion and Rights Advisor, WaterAid; Kate Brogan (kbrogan@InternationalMedicalCorps.org.uk) is WASH Advisor and Kweku Ackom (kackom@InternationalMedicalCorps.org.uk) is Senior Public Health Advisor, International Medical Corps; Michelle Farrington (mfarrington@oxfam.org.uk) works in Public Health Promotion HSP, Oxfam; Minja Peuschel (minja.peuschel@rb.se) is Co-lead Minimum Standards for Child Protection in Humanitarian Action for the Global Inter-Agency Child Protection Working Group; Nicole Klaesener-Metzner (Nicole.klaesener@rescue.org) is Environmental Health Technical Advisor, International Rescue Committee; Ricardo Pla Cordero (rplacordero@handicap-international.org) is Inclusion in Humanitarian Action Technical Advisor, Handicap International; Sue Cavill (suecavill@hotmail.com) is a freelance WASH consultant; Sarah House (sjhouse.majisafi@gmail.com) is a WASH/public health engineer and independent consultant in the UK.

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Box 1 What is incontinence?

Incontinence is a complex health and social issue, which involves the involuntary loss of urine or faeces or both. It can affect a wide range of people including:

- older people;
- men, women, and children with physical, intellectual, and/or psychosocial disabilities;
- women and adolescent girls who have given birth;
- women and adolescent girls who have suffered fistula (tear in the flesh adjoining the bladder or colon leaving a hole through which faeces or urine leak out) due to giving birth too young, from prolonged/obstructed childbirth, or from sexual assault;
- people with certain types of illness (such as cancer, diabetes, arthritis, and asthma) or who have had an operation (such as the removal of the prostate);
- people who have experienced highly stressful situations, such as conflict or disasters, and develop night-time bed-wetting;
- men, women, and children of all ages who simply have malfunctioning bladders or bowels.

Multiple sources including: authors' own work; Continence Foundation of Australia and International Incontinence Society websites

These questions are probably not ones that many of us have routinely considered as humanitarian or development professionals. But incontinence affects many more people than we imagine. The International Continence Society estimates that incontinence affects one in four women over the age of 35 years and one in ten adult men. Data for low and middle-income countries is lacking or not easily available, but it is quite probable that the figures are higher because of restricted access to health-care services and the higher number of young mothers. In conflict situations, like Syria, humanitarian workers have seen a dramatic increase of bed-wetting among children due to psychosocial distress.

Incontinence (see Box 1) can be caused by stress (on coughing, laughing, sneezing, or on exercise), urge (where a person has a sudden intense urge to pass urine), over-flow (inability to empty the bladder), as a result of poor functionality (mobility issues or unsuitable access to toilet facilities), or a combination of these reasons. The level and severity of incontinence varies significantly. This may range from having to manage leaking, smells and sores similar to nappy rash, to risking constant threat of urinary infections and bladder complications that can become life threatening if not properly managed (such as pressure sores in people with reduced skin sensation, if exposed to prolonged wetting and poor hygiene) (White, 2009). In addition to the stresses associated with managing the physical effects, incontinence is a hugely stigmatizing issue. It can lead to feelings of shame and embarrassment that can be very distressing and result in loss of self-esteem and exclusion from school, work, social life, and personal relations. In humanitarian contexts it has the potential to restrict access to services such as distributions of food or non-food items or to water or health services; to employment or other livelihood opportunities; and the ability to participate in decision-making processes, all of which in turn risk exacerbating social exclusion and vulnerability. For some people incontinence is an issue they have to deal with on a constant

Figure 1 Samples of reusable and disposable incontinence products for light to moderate incontinence: underwear, pads, and pouches (the three to the left are for women, the three to the right are for men)

basis, every day, some for a lifetime, and so is likely to pose significant challenges for their daily functioning.

A range of products for women and men with incontinence are available online and in supermarkets or pharmacies in higher income contexts. These include disposable pads or inserts, disposable diapers, reusable pull-up pants, and disposable pouches for men (see Figure 1). Bedpans, commodes, and disposable mattress protectors are also available. But accessing such items in a humanitarian emergency and low-income contexts is likely to be difficult, particularly due to the relatively high cost versus income levels and limited availability of disposable or reusable products. Accessing incontinence materials of an appropriate size for children, teenagers, or adults may also pose a challenge. Where products are usually available, the supply chain may be disrupted in humanitarian contexts. Challenges may also be faced in accessing appropriate information or accessing the required medical monitoring to estimate the evolution and required adjustments in bladder and bowel management.

Functional incontinence occurs when a person is aware of the need to urinate or defecate, but they are unable to get to, or use a bathroom. In emergency contexts and low and middle-income countries, household and public toilets may be a distance away, unsafe, and/or inaccessible. One man with disabilities in Uganda explained the consequences of not being able to get to a latrine in time:

> 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. (Wilbur et al., 2013)

Fear of soiling oneself can lead people to limit their consumption of food and drink. For instance, Anooda, a woman with disabilities in Bangladesh, explained how she relied on a caregiver to take her to the toilet. Often, when no one was able to help, she soiled her bed and would stay that way until someone was able to bathe her. She said, 'I was scared to eat and drink [before], no one would come and clean me'.

As a minimum, incontinence sufferers need easy and quick access to private areas to manage the changing and washing, drying or disposal of the protection materials, with access to adequate water supply and soap, as well as easy access to materials to soak up leaking fluids. Affected individuals, parents, and carers may also need guidance on how to deal with incontinence.

The scale of the issue is gaining increased attention in the humanitarian and development sectors, but the understanding of the specific needs and response capacity currently remains limited across sectors. Psychosocial teams from the International Rescue Committee (IRC), Save the Children, (SC) and from Handicap International (HI) have identified this as an issue for children affected by sexual violence or stressful events in conflict or disasters: for instance, humanitarian workers have seen a dramatic increase of bed-wetting among children affected by the Syrian conflict due to psychosocial distress. This means that parents must deal with urine-soaked clothes and bedding, night after night, whether they are on the move across Europe or living in camps for refugees or internally displaced people, or in unfinished buildings with limited WASH (water, sanitation, and hygiene) services.

> The war and the siege have left deep psychological scars on children, many of whom have witnessed extreme violence. Parents, teachers and health workers all report a range of common symptoms among children in their care, including bed-wetting and involuntary urination during class; recurrent nightmares; stuttering and speech difficulties; and social isolation…Khalil's older brother was killed and his father was unable to get to the area. He was wetting himself frequently and many pupils wouldn't play with him. With careful teacher support he now goes to the bathroom before every class and gradually he's begun to recover, feel safe and make friends. Today he's well liked and doing well in class. (Save the Children, 2016)

Furthermore, the increasing number of emergencies in middle-income contexts such as the Middle East and the Ukraine, which typically have ageing demographics with associated issues of poorer mobility, a higher pre-crisis prevalence of non-communicable diseases (such as cancers where incontinence is an associated issue), and conflict-related injuries linked to these events, means that there are likely to be increased numbers of individuals with incontinence in such humanitarian contexts. Oxfam also observed that a large proportion of the most vulnerable households in remote rural areas affected by the earthquake in Nepal had a family member who was either older or had disabilities, both groups that may be more affected by incontinence. During an evaluation of a WASH programme in the Seychelles implemented by the International Federation of Red Cross and Red Crescent Societies, one man noted that the most important thing he had needed, but had not been supported with, was adult nappies for his brother who had learning disabilities and suffered from incontinence. In a survey conducted by HI

and Help Age in 2014, 5.7 per cent of Syrian refugees in Jordan and Lebanon had a significant injury. People with spinal cord injuries (SCI) present mostly bladder and bowel issues after injury, needing lifelong management and follow-up. Within the Middle East project follow-up (in Jordan, Syria, Lebanon, and Iraq), HI identified over 350 SCI patients, presenting severe incontinence issues that are not properly managed in their living context. The stresses associated with not being able to effectively manage incontinence are clear for those who have talked with people who face this challenge, for example in Lebanon:

> I encountered many women that felt so helpless, as their husbands or sons had incontinence as a result of war injuries, leaving them in a wheel chair or with reduced mobility. (B. Hafskjold, personal communication, 2014)

And:

> I could feel the desperation of incontinence sufferers in the informal camps. One man, who had suffered a stroke, and his wife (who was pushing him in his wheelchair) clearly shared their problem of not having access to pads in front of a large group of people who had gathered around…I was struck by how desperate they were that they were prepared to share this stigmatising issue with a stranger who had just arrived in their camp, out loud and in public. (S. House, personal communication, 2014)

Incontinence poses multiple and severe practical and social challenges for the people who suffer from it, yet most humanitarian or development actors who have responsibilities across the WASH, health, disability, and protection sectors are not adequately acknowledging the problem and the practical needs associated with it. Perhaps some of us are not aware of it, or think it is only a small-scale 'niche' problem, or not an important lifesaving issue and hence not important in the immediate responses to an emergency, or even in medium or longer term contexts. Perhaps we are uncomfortable talking about it as, like menstrual hygiene, it tends to be a taboo subject and not a 'normal' topic of conversation. Or, if we are aware of it, perhaps we are simply 'putting our collective heads in the sand', as it feels too daunting, hoping it will go away or we can forget about it for a bit longer. The human rights to water and sanitation are indispensable for leading a life with human dignity and are a prerequisite for the realization of a range of other human rights, particularly the rights to achieve the highest attainable standard of living and health, to education and to gender equality (see The Rights to Water and Sanitation website). The Sustainable Development Goals (SDGs) have set targets on 'universal' and 'equitable' access to water, sanitation, and hygiene by 2030 (UNDESA, 2015). Most relevant to this issue is Goal 6.2, which states, 'paying special attention to the needs of women and girls and those in vulnerable situations' (UNDESA, 2015). In order to achieve this goal we will need to seriously engage with and respond to the needs of incontinence sufferers. Under the SDGs we are aiming for everybody everywhere, or 100 per cent of people, to have access to water and sanitation and to practise good hygiene behaviours…or do we mean just for the 100 per cent of people *who don't have incontinence?*

There are some exceptions where action has already been taken: Norwegian Church Aid (NCA) has been considering incontinence when designing and distributing

menstrual hygiene kits in emergency operations, for example in Liberia and Lebanon, meaning distribution which not only targets women of reproductive age, but also older people. It offers underwear, disposable pads (currently the larger sanitary pads used by women who have just given birth), reusable sanitary pads, or cloth for soaking up fluids. NCA is also currently including incontinence in its initial WASH assessment of the needs of people affected by the crisis in Burundi. Through this work it has found that incontinence is an issue for which WASH staff also need training and sensitization. In Iraq in 2015 HI distributed washable diapers (children and adult sizes), water, soap and containers for their washing, responding to a lack of/unaffordability of disposable diapers. One woman, acting on her own initiative, supported the production of disposable sanitary pads in Za'atari camp in Jordan (Venema, 2015). After hearing from people in the camp about their needs, she ensured that the machine she brought to the camp could also make incontinence pads.

Menstrual Hygiene Matters (House et al., 2012) included a short section on incontinence, as it was reported that sanitary products had been used to manage incontinence. Following this, WaterAid and the SHARE Consortium undertook a desk review to scope the scale of this problem (Giles-Hansen, 2015). The Water, Engineering and Development Centre (WEDC) (Jones and Reed, 2005), WaterAid (Jones and Wilbur, 2014), Oxfam GB (2007), and others, including disability-focused organizations such as CBM, have been working to increase the accessibility of WASH services. The elements of their work of particular relevance to incontinence have mainly focused on physical facilities such as commode chairs or bedpans and rails and lighting in facilities (see Figure 2). For instance, Anooda, whose experience was shared earlier, now has a shower and a flushing latrine next

Figure 2 Home-made commode chair: a toilet pan has been inserted into a metal seat and a container placed inside that then needs to be manually emptied into the toilet
Source: Jones and Reed (2005)

to her bed that she can use independently after advising WaterAid and IDEA on its construction. This has greatly improved her ability to maintain her hygiene and sanitation independently and with dignity. It has contributed to her improved comfort and well-being. Anooda explains,

> Someone used to have to carry me to the toilet and now I can do it myself… Now my suffering has been minimized…I was in pain and suffering. I feel happy. I feel free. I am grateful and want other people like me to get these services.

However WaterAid, WEDC, and Oxfam have not yet specifically considered the issue of low-cost disposable or reusable incontinence pads or underwear, or the support needed for people with incontinence, their parents, or carers, on good hygiene practices to manage this issue.

The WASH team of the International Medical Corps (IMC) in collaboration with HI has responded to specific requests from their health teams for accessible WASH facilities for people with disabilities in their Middle East programmes. While the IMC provided facilities, HI provided some disposable pads included in 'dignity kits', although the procedure for replenishment is not known, or whether the numbers provided were realistic to the long-term needs of the incontinence sufferers. The WASHplus project in Uganda has produced some guidance materials for training carers of people with HIV (USAID et al., 2008), which includes some guidance on incontinence and menstrual hygiene as well as how to make plastic pants from plastic bags that could be used by incontinence sufferers more generally. The victims of violence in conflict zones may have complex injuries that need dedicated and specialized bladder and bowel management inclusive of caretaker education and lifelong psychosocial adjustment for the injured, their families, and their environment. HI produced materials to guide people with these specific disabilities, medical and rehabilitation staff in north Syria and in a post-earthquake project in Pakistan – for instance on how to hygienically insert catheters – and also has provided disposable pads. A number of organizations also exist to support women with fistula, such as the West Africa Fistula Organization and fistula centres or hospitals such as in Ethiopia or Tanzania, which are assumed to have experience in materials that can be used by fistula sufferers. IRC, IMC, and some of the Red Cross/Red Crescent Societies provide postnatal hygiene kits or baby kits for mothers leaving hospital, some of which include larger disposable pads for post-partum bleeding, but not specifically for incontinence. Some medical focussed NGOs use disposable incontinence pads for the patients in their hospital facilities, but they do not always have programmes to support people with incontinence more genrally when they go home. In Burundi HI cooperated with Medicins sans Frontieres (MSF) to develop a continuum of care and follow up for the management of incontinence for fistula sufferers and social integration programmes to counter the stigma.

While the full extent of incontinence in low and middle-income contexts is not known, it is clear that it is a much bigger problem than is being acknowledged at present and the need for support for incontinence sufferers is an under-recognized issue. When raised with WASH professionals it has in some cases just been plain

ignored, perhaps put in the 'too hard to do basket', or colleagues have dismissed it as a minority or 'someone else's issue': 'HI will deal with that', or 'it's a health sector issue'. Our observations and discussions with institutions that work in the health, protection, disability, and WASH sectors suggest that no one is taking this issue as seriously as or on the scale that is needed, or willing to take responsibility and champion it. The limits are clear: HI or other disability-sector actors cannot be everywhere all the time and not everyone who has incontinence has other disabilities; health-sector actors may not have outreach services as well as hospital-based services; and the protection sector may be considering people's psychosocial health, but may not have the capacity to also deal with physical WASH needs.

But is it someone else's issue? *Surely it's EVERYBODY's issue*…and, like menstrual hygiene management, cuts across sectors. From the WASH-sector perspective, personal hygiene and the safe disposal of urine and faeces is our responsibility, and we are most commonly the ones to provide hygiene kits and other non-food items in the immediate stages of an emergency. So why are we ignoring those who have even greater and more stigmatizing hygiene needs than most?

It's time for us all – across sectors – to proactively acknowledge this issue. We should recognize it as part of our responsibilities and learn more about the scale and scope of this issue and the practical needs of incontinence sufferers in low-income and humanitarian contexts, particularly in the area of reusable protection materials and WASH needs. We need to start acting to incorporate incontinence as a standard part of our programme responses. Let's start talking about this issue and work together to ensure that we uphold the best standards on inclusive approaches. Let's make a difference to the health, dignity, and well-being of some of the most vulnerable people in the world and make sure that hygiene promotion, as well as ensuring access to water and sanitation for all, really means for *all*…including incontinence sufferers.

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