

MAPPING OF SUPPORT FOR PEOPLE LIVING WITH INCONTINENCE IN HUMANITARIAN CONTEXTS

THROUGH THE LENS OF WASH, GBV AND ASRH

MAIN REPORT
DECEMBER 2022

VERSION 2

“There is nothing as undignified as leaking urine or faeces”



NORWEGIAN CHURCH AID
actalliance

ACKNOWLEDGEMENTS

Sincere thanks to all of the contributors to this mapping process, whether through participating in the NCA webinar and online survey, being an interviewee in the key informant interviews (KIIs) or focus group discussions (FGDs) or sharing information by email or through documentation. In particular, the openness to share both the progress and successes, as well as the challenges and barriers preventing more confident action in relation to incontinence in humanitarian contexts, has been particularly appreciated. The increasing interest and enthusiasm for learning how to work better with, and support people living with incontinence in humanitarian contexts, has been encouraging. It offers hope for improving the opportunities for people living with incontinence in humanitarian contexts, a very marginalized and overlooked group of people, to be able to live their lives with dignity.

Participants in the mapping process, including participants of the online survey, KIIs and FGDs, were from Norwegian Church Aid (NCA) and 22 other agencies. The participants were currently

based in and working on humanitarian responses in 13 countries and also shared experiences from working in a range of other humanitarian responses in other country contexts. Examples were shared from countries in Africa, Asia, the Middle East, Europe, Central America, and the South Pacific.

The work was initiated and facilitated by Åshild Skare and Peter Noel Cawley from the NCA WASH team, with contributions from NCA GBV and ASRH teams. The process for the mapping was led by independent consultants – Dr Sarah House and Dr Chris Chatterton.

This mapping process was made possible by financial support from the Norwegian Ministry of Foreign Affairs. The contents are the responsibility of the NCA and do not necessarily reflect the views of the Ministry. The mapping process included input from various stakeholders, therefore the report does not reflect solely the views of NCA.

For a list of contributors to the NCA mapping process, please refer to [Annex I](#).



Norwegian Ministry
of Foreign Affairs



NORWEGIAN CHURCH AID
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IMAGE ON FRONT PAGE

Janet has severe rheumatoid arthritis in her knees and ankles, which prevents her from being able to walk to the toilet. World Vision and partners have been working in Vanuatu, to support people living with disabilities with managing their incontinence.

“Thank you so much” – “With my rheumatic arthritis I can’t put weight down on my legs, so I can’t even walk a short distance to the toilet. Even though I have a toilet that is inside my house, I still can’t get to it by myself and so I have to go to the toilet in a bucket underneath my bed through the wooden slats. I am just so so grateful for this toilet, that I can use by myself with dignity next to my bed.” “Please will you give one to my sister with rheumatoid arthritis who lives in Gaua”,

Janet, Port Vila

(Credit: Allison Coleman / World Vision Vanuatu / 2021)

THE MAPPING REPORT AND SUPPORTING DOCUMENTS

This document is part of a set of four documents generated as a result of the mapping process:

Mapping support for people living with incontinence in humanitarian contexts – Through the lens of WASH, GBV and ASRH:

- **Summary report**
- **Main report**
- **Supporting document 1** – Longer case studies
- **Supporting document 2** – Practical resources

The findings and recommendations presented in this report, represent the outcome of the data collection and analysis carried out by the external consultants through the mapping process. NCA has been consulted throughout the process. However, the conclusions and final reports have been prepared by the external consultants.

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TERMINOLOGY FOR INCONTINENCE/CONTINENCE PRODUCTS

There are a lot of different products available for managing incontinence, from pads through to various devices, such as catheters and stoma bags. We are conscious that the terms used, particularly in regard to body worn pads, vary across the world. We have taken guidance from different sources on this. In particular, the International Continence Society (ICS) report on ***'The terminology for single-use body worn incontinence products'***, which was published in 2020.

We have therefore tried to use basic terms, such as 'incontinence pads' or other commonly used terms, to simplify and make the report as widely accessible as possible. In relation to the term 'adult diapers' (or 'nappies'), many healthcare professionals and adult users, do not like to use this term, because of the fear that it may further stigmatise people using these products, due to the linkage in most people's minds, to use by babies and young children.

However, these terms are still regularly used in healthcare settings and in everyday language in many countries of the world. And whilst not wishing to add to the burden of those living with incontinence and to follow the principle of 'do no harm', we recognize that its meaning is widely understood across many countries. We have therefore decided to still sometimes use the term here, but in quotes and/or brackets, in recognition of its potential stigmatising nature. In addition, in some countries, the products are known by the most well-known brand, such as 'Pampers' in East Africa. We have tried to keep away from names of brands, but recognise that within specific country contexts, these may need to be the terms used, to ensure understanding locally.

ACRONYMS

| ACRONYM | DESCRIPTION |
|-------------------|---|
| APL | Assistive Product List |
| ASRH | Adolescent, sexual, and reproductive health |
| CLTS | Community-led total sanitation |
| CVA | Cash and voucher assistance |
| DCA | DanChurchAid |
| FBO | Faith based organisation |
| FGD | Focus group discussion |
| FGM | Female genital mutilation |
| GBV | Gender based violence |
| GHA | Global humanitarian actors |
| GWC | Global WASH Cluster |
| HIF, ELRHA | Humanitarian Innovation Fund, ELRHA |
| HP | Hygiene promotion |
| HO | Head Office |
| IAD | Incontinence Associated Dermatitis |
| IASC | Inter-Agency Standing Committee |
| ICS | International Continence Society |
| IDIs | In-depth interviews |
| IDPs | Internally displaced persons |
| KII | Key informant interview |
| LMIC | Low- and middle-income country |
| LSHTM | London School of Hygiene and Tropical Medicine |
| MHM/MHH | Menstrual hygiene management / Menstrual health and hygiene |
| MHMIE WG | Menstrual Hygiene Management in Emergencies Working Group |
| MHPSS | Mental health and psycho-social support |
| MoH | Ministry of Health |
| MOOC | Massive open online courses |
| NCA | Norwegian Church Aid |
| NFI | Non-food items |
| NGO | Non-governmental organisation |
| NMFA | Norwegian Ministry of Foreign Affairs |
| PDM | Post-distribution monitoring |
| PHC | Primary health care |
| SCI | Spinal cord injury |
| TAP | Training in Assistive Products |
| TBA | Traditional birth attendant |
| UTIs | Urinary tract infection |
| WASH | Water, sanitation, and hygiene |

For acronyms of the organisations of contributors to this mapping process – please refer to **Annex I**.

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LONGER CASE STUDIES - INCLUDED IN SUPPORTING DOCUMENT 1

NCA – Humanitarian response case studies

| | | | |
|----------|-------------------|-------------------|---|
| CS-NCA-A | 2014 | Syria and Lebanon | NFIs for older people |
| CS-NCA-B | 2015 | Iraq | Discussions with older people on NFI incontinence distributions |
| CS-NCA-C | 2016 | Greece | WASH response to the Europe refugee crisis |
| CS-NCA-D | 2020 | Ethiopia | Learning from MHM and disability for incontinence |
| CS-NCA-E | 2021 | South Sudan | Cash e-Vouchers for incontinence |
| CS-NCA-F | 2022 | DRC | Opportunities for WASH, GBV, ASRH engagement |
| CS-NCA-G | 2022 HEKS-EPER | Ukraine | Non-WASH actors working on incontinence |
| CS-NCA-H | 2022 DCA | Bangladesh | Opportunities for ASRH engagement |
| CS-NCA-I | 2022 | Somalia | FGM and fistula |

Global humanitarian actors – Humanitarian response case studies

| | | |
|-----------------|-------------------------------|--|
| CS-GHA-A | Regional Syria Response | Loving Humanity Washable products |
| CS-GHA-B | Ukraine | Global WASH Cluster taking the lead on incontinence in Ukraine |
| CS-GHA-C | Ukraine | Incontinence actions across contexts in Ukraine |
| CS-GHA-D | Vanuatu | World Vision Supporting people with disabilities |
| CS-GHA-E | Global | HI Supporting people with spinal cord injuries |
| CS-GHA-F | Global | IRC, IFRC WASH responses supporting children wetting the bed |
| CS-GHA-G | Global | MSF Integrating incontinence into health responses |
| CS-GHA-H | Global | UNFPA & partners Fistula prevention & response |
| CS-GHA-I | Global | UNICEF, WHO Supply and innovation – including in Ukraine |

SECTION 1

EXECUTIVE SUMMARY

“People’s continence is the root to their dignity”

(Humanitarian actor)



1. EXECUTIVE SUMMARY

INTRODUCTION

Incontinence

This is a condition where an individual is unable to control their bladder and/or bowel, and where they leak, either urine, or faeces, or both. A wide range of people live with incontinence and it has significant impacts on the physical and mental health of the individual and their caregivers. It can also restrict their ability to engage in activities outside of the home and it has significant impacts on a persons' ability to live with dignity. It can also be life threatening. The level of severity of the incontinence can vary significantly and can affect people day, night, or both.

Norwegian Church Aid (NCA) and incontinence

NCA is a faith-based ecumenical non-governmental organisation, which works for global justice, in humanitarian contexts and in long-term development with communities, to address the root causes of poverty. NCA started working on this issue, in its humanitarian responses in Liberia in 2012, Lebanon in 2014, Iraq in 2015 and Tanzania in 2016. This mapping report has been initiated by NCA, to reflect on how far NCA and other global humanitarian actors (GHA) have progressed and look at what is needed going forward.

Objectives of the mapping process

These are: a) To map how humanitarian actors globally, are currently engaging with and supporting people living with incontinence in their humanitarian responses; b) To map to what extent NCA is currently addressing incontinence in its humanitarian responses; and c) To provide guidance on how NCA

“People’s continence is the root to their dignity”

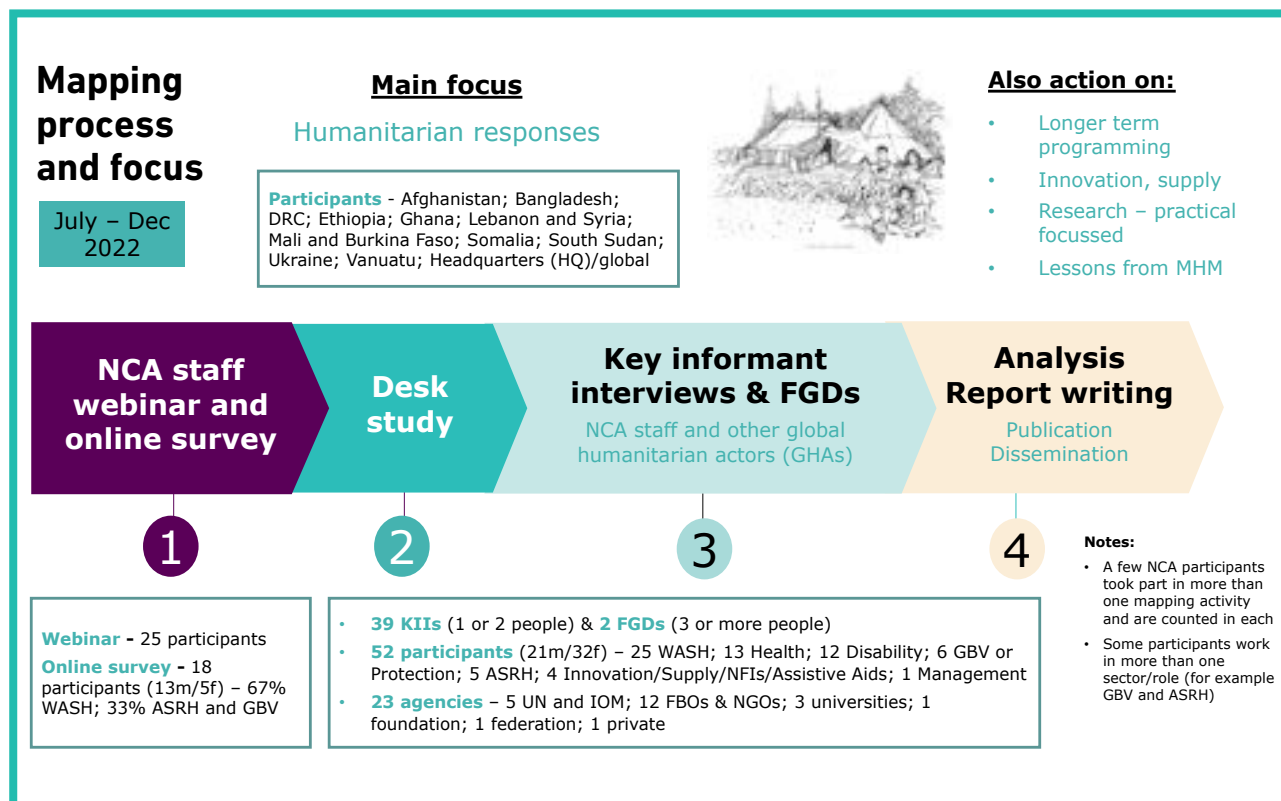
(Humanitarian actor)

can strengthen the integration of incontinence in its humanitarian responses, with a particular focus on Water, Sanitation and Hygiene (WASH); but also considering Gender Based Violence (GBV); and Adolescent Sexual and Reproductive Health (ASRH). It is also hoped that the resulting report, will encourage other actors to increase their engagement in supporting people living with incontinence in humanitarian contexts.

Process

The mapping was undertaken between July and December 2022. It was led and NCA WASH Team, with support from the GBV and ASRH teams. Independent consultants, Dr Sarah House and Dr Chris Chatterton, supported the process. The mapping was undertaken in stages, starting with an introductory webinar and an online survey with NCA staff (WASH; GBV; ASRH); a desk study; and key informant interviews (KIIs) and group discussions (FGDs). These were undertaken with NCA teams and global actors working in humanitarian contexts and on incontinence. Refer to **Fig 1** - for an overview of the activities, timeline and participants in the process.

FIG 1 - NCA INCONTINENCE MAPPING TIMELINE, PARTICIPANTS AND PROCESS¹



FINDINGS

People living with incontinence

A wide range of people may live with incontinence – older people; children/teenagers who start wetting the bed due to traumatic experiences; women and girls, due to problems during the birthing process, including women and girls who have undergone the more extreme forms of female genital mutilation (FGM, Types III and IV); women, men, girls and boys affected by GBV; people with different kinds of disabilities, including spinal cord injury; people with chronic illnesses, such as asthma, diabetes and a range of other conditions; and women going through the menopause process. Males, as well as females, may live with incontinence. This mapping process, has not considered the management of babies’ faeces, as a child cannot be considered incontinent medically, until they are over 5 years of age². Toilet training is also considered part of the normal developmental learning, and is seen as socially acceptable. However, some of the practical actions supporting people with incontinence, will also be of use in the management of babies’ faeces.

Why integrating incontinence into humanitarian responses is so important

People living with incontinence can face a range of health and social-related problems, from issues with odour and skin damage, to urinary tract infections (UTIs), bladder complications and Incontinence Associated Dermatitis (IAD) (similar to problems, more commonly known as ‘nappy rash’ in babies). This is as well as sores (commonly known as pressure sores, or bed sores), which in some cases, can become infected and be life-threatening and can even lead to death. These are particularly a problem, for people living with incontinence who are immobile. Therefore, living with incontinence, can potentially have a serious impact on your health. Incontinence, can also have a big impact on mental health and wellbeing, with anxiety and depression being common, due to the significant impacts, it can have on a person’s life.

“For people with the condition of spinal cord injury, the issue of incontinence is a huge survival issue”

(Humanitarian disability sector actor)

Easy access to appropriate water, sanitation and hygiene (WASH) facilities, are essential to be able to manage the leakage and contain the odour of urine or faeces, to allow people living with this condition to be able to live with dignity and to be able to engage in daily activities outside of the home. People may also need access to other non-food items (NFIs), such as catheters, with associated urine bags, incontinence/continence pads, mattress protectors and soap and water. This is, as well as needing the ability to wash, dry and dispose of incontinence related products. People living with incontinence and their caregivers, also need access to health information, on how to keep healthy and well.

But in humanitarian contexts, where people are on the move, or are living in poorly serviced refugee or IDP camps, access to WASH facilities may be difficult. People may also have limited access to soap and water, as well as privacy, to be able to wash and dry soiled clothes, pads, bedding, or cleaning and drying a urine-soaked mattress. Caregivers of people living with incontinence, may also be severely restricted in their lives and be unable to work, join in community activities, pick up aid items, or if the caregiver is a child, to go to school. They may also not know where to ask for help and support.

The true scope and scale of the problem is not fully known, largely due to the taboo surrounding incontinence, which makes planning for responses difficult, although there is increasing experience of humanitarian agencies, providing support at scale, particularly in relation to supporting parents and children, who have been traumatized by conflict, or other highly distressing experiences and have started wetting the bed. Examples of this type of support, have been shared from humanitarian responses in the Syrian response, Greece, Iraq and Honduras. Large-scale support has also been provided for older people in Ukraine, and efforts have increasingly been made to support people with disabilities, particularly people living with spinal cord injury, across humanitarian contexts. Responsibilities for supporting people with

incontinence, also cuts across professions and sectors. For example, WASH, general health, sexual and reproductive health, physiotherapy, protection, GBV, older people and people with disabilities, logistics, etc. Yet, it remains an overlooked issue by most sectors, partly because the issue is a hidden issue, and also, as sectors can say, that it is not their responsibility, but another sector's responsibility, because the responsibilities are not yet clearly defined across sectors.

Humanitarian contexts where action has been undertaken

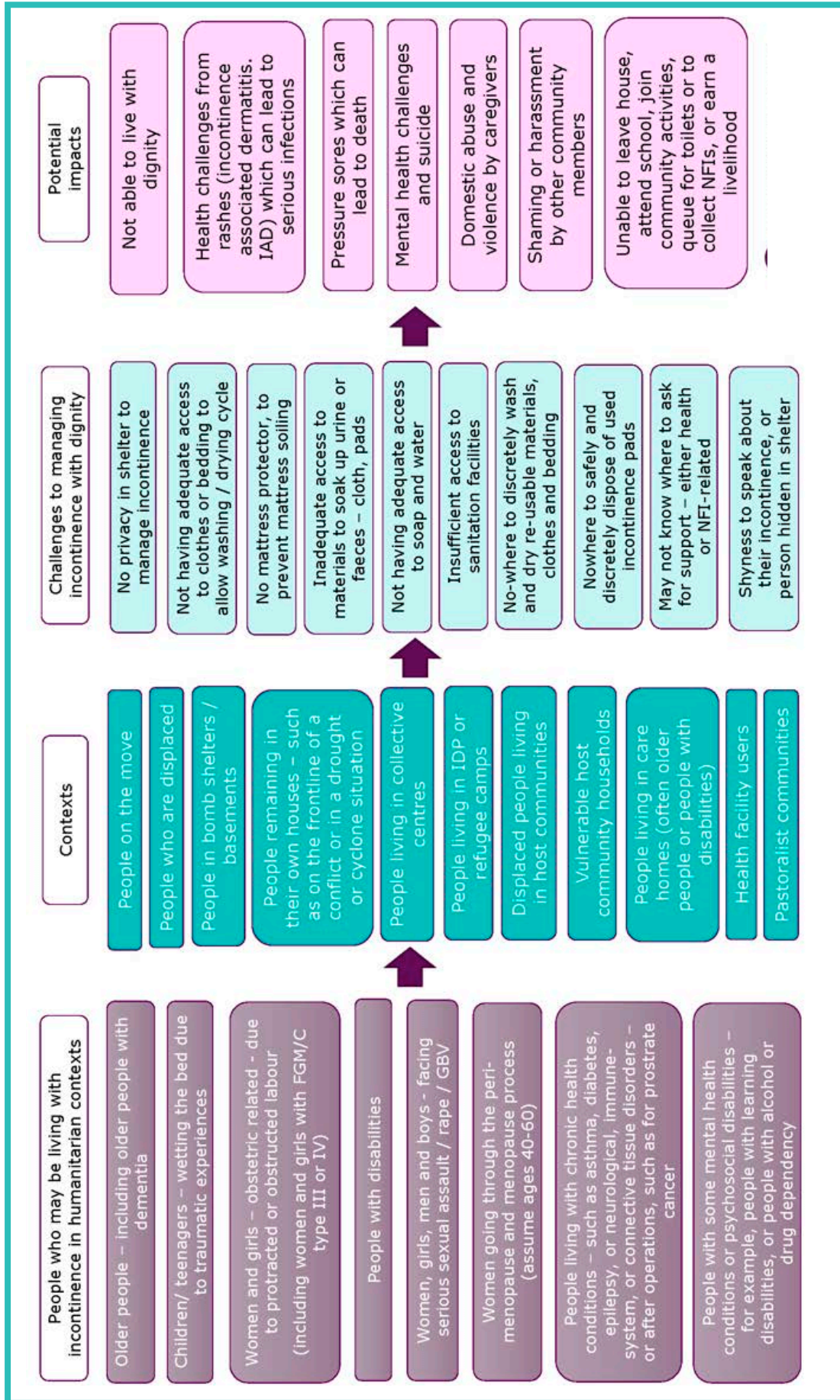
Respondents highlighted different locations in which they have made efforts to support people living with incontinence. These included: people on the move; and people remaining in their houses, such as in chronic humanitarian crises and on the front-line of conflicts; people in bomb shelters/basements; people in collective centres; people in care homes; people in IDP or refugee camps, or living in host communities; people visiting and as in-patients in health facilities; pastoralist communities; and people living in challenging locations, where access is difficult due to conflict or remoteness. Examples of action in programming by humanitarian actors, have been shared from a range of countries, such as: Liberia; Tanzania; the Regional Syria Response; Iraq; Greece; Honduras; Somalia; DRC; Ethiopia; South Sudan; Ukraine; East Asia; Vanuatu, and Algeria.

See **Fig 2** - for an overview of people affected contexts in which people may be living with incontinence, challenges faced with the management of incontinence and the potential impacts.

“People are hidden and suffering often in silence – there is no support”

(WASH sector humanitarian actor)

FIG 2 - PEOPLE LIVING WITH INCONTINENCE IN HUMANITARIAN CONTEXTS AND IMPACTS OF NOT BEING SUPPORTED





Monitoring of pilot e-Voucher scheme vendors shops and processes, South Sudan

(Credit: Bereket Seifu / NCA / 2021)

NCA ENGAGEMENT

NCA started providing support on incontinence in humanitarian contexts in Liberia in 2012 and Lebanon in 2014. NCA and partners, started distributing extra soap and other hygiene items and sanitary pads for women for menstruation, but did not set an upper age limit, and hence older women, were also using them to manage their incontinence. They continued this work in other countries and after asking for feedback, later also distributed incontinence pads (diapers), instead of sanitary pads. This initial learning, then led to a range of other actions by NCA and partners.

Progress at global level

This has included working to strengthen cross-sectoral engagement and learning from other work, particularly menstrual hygiene management (MHM). NCA's work on the ground, also inspired the start of discussions and action across humanitarian agencies at global level, which subsequently, lead to the formation of a global informal email group on incontinence in humanitarian and low-and middle-income (LMIC) contexts and other actions. NCA have also been integrating incontinence into wider trainings and have developed an online training on MHM and incontinence in humanitarian contexts³. They have also engaged with the media on this issue in Norway, together with MHM, and established an indicator on incontinence, in their Strategic Partnership Agreement (SPA) with the Norwegian Ministry of Foreign Affairs (NMFA). The NCA Head Office (HO) has been providing encouragement and support to country programmes and they have also initiated this mapping process. This has identified a range of actions which have been happening

globally, but which were not well known, and has also led to a number of new members, joining the global informal email group.

NCA country humanitarian responses with incontinence-related actions

These have included actions in: Liberia (2012), Lebanon and Syria (2014-2022), Iraq (2015-2019) and Tanzania (2016)– supporting older people with non-food items (NFIs) for incontinence;

Greece (2016) – provided WASH responses in the European refugee crisis; and in South Sudan (2021) – undertook a pilot for e-Voucher cash support for vulnerable households, which considered households with people living with incontinence, in a camp and the host town⁴.

In DRC – The GBV, ASRH and WASH teams have supported work in a fistula hospital; and in Ukraine (2022), in partnership with HEKS-EPER (Swiss Church Aid), they are distributing NFIs. In Ethiopia (2020-2021) – the team has been building on their MHM⁵ and disability-focused work and are currently supporting the International Organization for Migration (IOM) to undertake an assessment in Gambella, to investigate innovation needs for incontinence. The team in Bangladesh (2022), working through Danish Church Aid (DCA), have been supporting SRH services, and occasionally refer people to a local fistula hospital. In Somalia, some support is also provided for fistula, which includes women and girls who have had female genital mutilation (FGM).



Distribution of incontinence pads to older people in the Mosul, Iraq response, 2015

(Credit: NCA / 2021)

NCA staff and partners current knowledge and experience on incontinence

The online survey aimed to understand the current knowledge and experience of NCA staff and partners, and the barriers to engagement, as well as priorities to help the NCA staff and partner teams, to be able to strengthen their work going forward. In response to the question on rating their current knowledge on incontinence, there were a reasonably wide range of responses. Half of the participants indicated they were in the 'less knowledgeable' half of the scale and half in the 'more knowledgeable' half of the scale. Only a few shared that they had undertaken actions related to incontinence, such as providing NFIs, or improving WASH facilities for a person affected by this condition. In relation to having spoken with someone with incontinence, out of 18 respondents: 12 people responded 'never', 3 said 'only once', and 4 people said 'occasionally'. The key barriers to engage with people with incontinence, revolved around: a lack of knowledge, lack of funds, not knowing how to talk about the subject, and not

knowing how to respond practically. The next group of barriers, included not believing it is an important or priority issue, and feeling that it is not life-saving, feeling embarrassed to talk about the subject and not wanting to offend. In terms of support, or actions to be able to strengthen engagement, the highest ranked were opportunities to share experiences with other programmes, seeing case studies, showing how this issue had been practically responded to, and guidelines, checklists and capacity building. But following not far behind, was also increased engagement by senior management and funding opportunities.

See **Section 4** - for further details of the work of NCA in incontinence in humanitarian contexts, along with more information on successes and challenges, as well as case studies and learning from the work of the NCA in this area.

GLOBAL PROGRESS AND CHALLENGES

This section summarizes the progress globally by NCA and other global humanitarian actors on supporting people with incontinence in humanitarian contexts. See **Sections 5 and 6** - with more details and case studies.

Global humanitarian leadership, cluster and cross-sectoral coordination

PROGRESS

Increasing interest and engagement in incontinence by WASH Cluster leadership, has been shown in the Ukraine response. There have also been occasional discussions occurring through coordination mechanisms, particularly in hygiene promotion (HP) working groups.

IMPACT OF CLUSTER COORDINATION LEADERSHIP ON SUPPORT FOR OLDER PEOPLE LIVING WITH INCONTINENCE IN UKRAINE

Widespread action supporting older people with their incontinence in Ukraine, has clearly been improved, because of the WASH Cluster's leadership on this issue. Being interested, committed and humble enough, to not just do what has always been done, and to start from first principles, to try and find solutions for the people most vulnerable in this response, has led to widespread action. This was focused on coordinating multiple agencies, to consider appropriate aid to the older target population.



GAPS/BARRIERS

There is still limited commitment at cluster and organisational leadership levels, at both global and response levels, with most cluster leadership across sectors, not discussing responsibilities related to incontinence. Incontinence, is also not the responsibility of one sector and there is no clear lead across sectors, which adds complications to encouraging a feeling of responsibility for action. Respondents also shared that over the previous years, there has been a change in leadership and power in humanitarian organisations, which is seen to pose challenges for real accountability; positive stories seem to be most important, which can mean the challenges are more hidden. Respondents also shared challenges from having limited time and limited numbers of staff, including with less hygiene promotion staff in senior leadership levels, and staff having a high workload and a wide range of responsibilities. Issues which are more hidden and complicated, as they fall across sectors, like incontinence, also do not tend to be prioritized over simpler one-sector issues (such as access to toilets). The variations in the condition and wide range of people possibly affected by incontinence, also poses challenges, as it means, humanitarian actors, need to understand a wide variety of needs and how to engage with a range of different stakeholders. For example, how to engage with women or men who have fistula due to serious sexual assault, would be

different to the routes and ways to engage with older people. Politics and competition between agencies, for areas to work and for funding, also pose challenges to ensuring quality of responses, including to consider issues such as incontinence. For example, it is assumed that working on this issue, will reduce the numbers of beneficiaries which can be supported. This is seen as negative, in terms of attracting funding from donors. Gaps in honesty over challenges within programmes and competition between sectors, including over control of funds, can also pose barriers. In addition, gaps in data on prevalence and a bias towards requiring quantitative evidence, versus using common sense, listening to people and prioritising quality of life and dignity, also pose and will continue to pose, challenges to engagement.

EVERYONE'S ELSE'S RESPONSIBILITY – AND HENCE NO-ONE'S RESPONSIBILITY?

A number of humanitarian actors shared their concerns about the risks for who takes responsibility: *“One of the challenges, is that it seems blatantly relevant to protection, health, reproductive health, WASH – so it should be like MHM. It is an obvious thing to do, but it is at risk of being an orphan child – It’s everyone else’s responsibility and hence it ends up being no-one’s responsibility”.*

General across all sectors



PROGRESS

A significant step forward, has been more specific inclusion of incontinence in the WASH Chapter, Sphere standards in 2018⁶. The global informal email group on incontinence in humanitarian and LMICs, established in 2016, pulled together informal guidance on supporting people with incontinence (2019), as a starting point for action⁷ and in 2021, the UNFPA *Guiding principles for clinical management and program development - Obstetric Fistula & Other Forms of Female Genital Fistula*, has been updated⁸. Protocols have also been developed by Humanity and Inclusion (HI), to support people living with

spinal cord injury with self-catheterization⁹. There has also been increased engagement of a few donors, and a number of efforts are being made, related to innovation and supply on solutions for incontinence. A practical website is also being supported with advice on continence materials, called the Continence Product Advisor website¹⁰, supported by Southampton University, University College London, the International Continence Society and the International Consultation on Urological Diseases. This includes descriptions, specifications and feedback from product users.

Positive steps, have also been made to start to learn about people's experiences of living with incontinence in humanitarian contexts, through research and some from practical action on the ground and increasing sharing of learning.

“We tend to use a ‘cookie cutter’ kind of approach, where one size is assumed to fit all. As we have to work quickly in emergencies, so we tend to do what we know, and this includes the standard template, that does not include considering incontinence”.

(WASH sector humanitarian actor)



GAPS/BARRIERS

A range of guidance and checklists for minimum actions, are still required for different actors working in different roles and contexts, from doctors to community workers. Simple one-page checklists on responsibilities, do not yet exist and there are gaps in the availability of assessment and monitoring tools. Implementing actors need to be at the centre of developing such guidance and tools, to ensure that they relate effectively to the practical realities on the ground, when working with communities on a daily basis. Challenges also exist from decreasing budgets, against multiple priorities, and the costs of flying in NFIs in the early stages of humanitarian

responses. Incontinence is also still not a priority for most humanitarian donors and there is a need for more clarity as what they expect in relation to this issue, during their calls for proposals. Innovation/identification of existing products and supply and distribution mechanisms, need to continue and getting feedback and suggestions from people living with incontinence and their caregivers, needs to increase. In most emergencies, there are no targets, or monitoring of actions related to incontinence.

Fig 3 – provides an overview with examples of the key actions undertaken by humanitarian actors.

“Donors are increasing their demands, requiring all programmes to be inclusive, and so getting more technical partners for disability inclusion. But few are working to ensure inclusive WASH”

(Disability and WASH specialist)

FIG 3 - EXAMPLES OF PROGRESS ON INTEGRATING INCONTINENCE INTO HUMANITARIAN RESPONSES

| EXAMPLES OF BARRIERS / GAPS TO GLOBAL ACTION | COUNTRY - examples | ORGANISATIONS ACTIVE - examples | HUMANITARIAN PROGRAMMING ACTIVITIES - examples | SUPPORTING ACTIONS ACROSS SECTORS |
|---|--|--|---|--|
| Limited commitment of Cluster leadership across sectors, globally and nationally & of organisational leadership on this issue | Syria/ Jordan/ Lebanon | Loving Humanity, NCA, HI, UNHCR | Distribution of disposable and reusable pads and other NFIs, UNHCR protection team active in Syria response | Research and learning from people living with incontinence and their caregivers – people with disabilities; older people; women with obstetric fistula; children (ELHRA/HIF and Water for Women) |
| Limited prioritisation and clarity on requirements for action by donors | Iraq | NCA, MSF, HI | Distribution of WASH NFIs, advice on catheters, MHPSS support to parents on child bed-wetting | Informal global email group across sectors since 2016 – > 100 members - multiple sectors (2022) |
| Lack of knowledge and confidence of humanitarian actors across sectors on how to respond | Greece | IRC, IFRC, NCA | Distribution of WASH NFIs, to people on the move, through hygiene kiosks in camps & using vouchers through health services | Incontinence indicator in donor funding agreement (NCA – Norwegian Ministry of Foreign Affairs) |
| Feeling embarrassed to talk about this issue | Honduras | IFRC | Phone line for parents of children wetting the bed to ask for assistance | Organisational practical guidance for people with disabilities (HI and CBM) and collation of informal guidance (informal email group) |
| Fear of causing offence and not knowing how to talk about this issue | South Sudan | NCA | Pilot of e-Voucher scheme for vulnerable households, with incontinence as a criteria | Innovation and supply focussing on incontinence NFIs for people with disabilities (UNICEF and WHO) |
| Lack of practical guidance and tools for different actors – from doctors to community workers across sectors | Ukraine – 2018 - 2021 | WASH Cluster (WC), People in Need, Caritas, NRC, UNICEF, IOM, ArcheNova, Proliska, VostokSOS, ADRA | WASH Cluster Coordination leadership – engagement with Age and Disability TWG; toilet chairs; establish NFI requirements for older people in hygiene guidelines | Production of reusable incontinence products (Loving Humanity, Jordan; World Vision, Marma Laef, Vanuatu) |
| Not enough funding | Ukraine - 2022 | WC, Government of Poland, UNICEF, NRC, Swiss Church Aid/NCA, HI, IOM, OXFAM, WHO | WASH Cluster Coordination leadership – mandatory action, multiple agencies including NFIs for incontinence, in Special Needs hygiene kits, support in care homes, collective centres etc. | Integration into wider trainings, such as MHM & incontinence training (NCA) and OXFAM SaniTweaks training (OXFAM) |
| Not believing it is an important issue - as it is perceived as not life-threatening and not an emergency issue | Vanuatu | World Vision | Supporting older people and people with disabilities in accessing re-usable absorbent and cleaning products and local toilet chairs | Publications and presentations / webinars (Global WASH Cluster & Sanitation Learning Hub) |
| Under prioritisation on rights to care and dignity and over-focus on numbers and medical interventions for life-saving only | DRC, Somalia, Burundi and elsewhere | Hope Hospital, UNFPA Fistula Foundation, NCA, MSF and a range of partners supporting fistula hospitals | Support to fistula hospitals including WASH services; surgery; GBV training of staff; community engagement to reach people living with fistula | |
| Limited data on prevalence and under-valuing learning from the experiences of people living with this issue and quality of life | Ethiopia | IOM, NCA | Building on experiences with MHM and disability, learning needs for products for incontinence | |
| | Bangladesh | NCA, UNICEF, UNFPA | Support for SRH services and fistula care, informal TWG on MHM & incontinence (2018-2000) | |

Additional findings and conclusions – WASH

PROGRESS

The WASH Cluster coordination team in Ukraine, provided leadership on the importance of supporting people with incontinence¹¹ and a number of WASH organisations have already started trying to support people with incontinence, in a number of humanitarian contexts. A range of approaches have been used, to try and provide NFIs to people living with incontinence and the WASH sector has improved in terms of needs identification. In some cases, organisations are more likely to ask people what needs are and

what are their preferences. A link has sometimes been made between incontinence, MHM and hygiene kits. Research has also been undertaken, on people's experience of incontinence in humanitarian and LMIC contexts, which has focused on their WASH needs and priorities for support. WASH sector actors, have also had a key role on getting incontinence talked about and on the humanitarian agenda.

“We came across a house which had a pathway installed to a latrine for a young man in a wheel-chair... but the latrine was tiny, and the man clearly couldn't use it alone. His father also said that he has mental disability as well, so that he doesn't actually know when he needs the toilet, and regularly soils himself. On the ground along the path to the latrine were piles of soiled clothes, which the family had dumped outside as they didn't have enough water to wash them, and couldn't keep them in the house for the smell”.

(WASH sector humanitarian actor, Rohingya camps, Bangladesh, 2019)

GAPS/BARRIERS

Commitment is not yet widespread in WASH Cluster coordination mechanisms at global and response levels and there is no specific person responsible to make sure that incontinence is responded to, in the WASH Cluster coordination mechanism at response level. Focus tends to be more on access to sanitation and water supply, with less attention on hygiene promotion and the needs of more vulnerable groups. The sector is still in the early stages of learning on how to identify and distribute NFIs and provide other support, to people with incontinence and their caregivers. Lack of knowledge on how to discuss this subject and fear of causing stigma, has caused barriers for some actors to engage

with people who live with this issue, although a range of agencies have been supporting people affected by incontinence across contexts. There is also often a high turnover of staff and many staff without prior humanitarian, or WASH experience, are working in WASH and community mobilization roles. The WASH sector is also often highly biased towards male actors and in some countries and it can be difficult for female staff to work in the field. This limits, being able to speak with females on sensitive issues.

Additional findings and conclusions – Protection and GBV

PROGRESS

Large-scale provision of incontinence absorbent products, has been reported by UNHCR, Protection teams, to have occurred in the camps in the Regional Syria Response. More than 18,000 people with disabilities in the camps, were provided with diapers in 2021. Protection actors, have also been involved together with WASH actors in other responses, working to support caregivers of parents of children wetting the bed. Protection and GBV sector, as well as Health actors, have also been providing some support to females and males affected by GBV, resulting in fistula.

“It is by God’s grace I am here; else I would have poisoned myself by now. Because the thing worriers me. If a man comes to me, they leave me”.

*Woman who has undergone fistula surgery, Ghana
(Quote documented by Research and Grant Institute of Ghana/2021)*

GAPS/BARRIERS

Currently there is a gap in raising awareness on how to prevent violence against people living with incontinence by their caregivers. Referral pathways need to be clarified, for a person living with incontinence, particularly if abuse is suspected. A big challenge will be how to support people discretely, who have started being incontinent, or have fistula due to rape, or other forms of violence. Particular advice is also needed, on how to encourage males to come forward for support, who have faced sexual violence, or sexual torture, which has resulted in fistula. There is still a need to integrate questions on incontinence and needs, into GBV assessment processes. There is currently very little, if any, involvement of older people, or people with disabilities, in safe spaces in humanitarian contexts, and although there is an increase in popularity in use of cash transfers, it is also suspected, there may still be hidden protection risks.

Additional findings and conclusions – ASRH/SRH and fistula care

PROGRESS

SRH efforts on promoting safe births, contributes to a reduction in risk for obstetric fistula and some SRH actors support safe spaces, which also have a medical officer and sometimes mental health and psychosocial support (MHPSS) staff present. The possible link between female genital mutilation (FGM) and increased risk of fistula, is controversial, but analysis across studies¹², has found that women who have undergone the more severe forms of FGM (Type III and IV), are at increased risk of fistula. A number of fistula hospitals also exist, which are supporting surgeries for women

affected by fistula, who are living in humanitarian contexts, and some intermittent surgeries are also being implemented in existing health facilities and services. An ELRHA/HIF-funded research has been led by the Research and Grant Institute of Ghana (ReGIG), on the WASH needs of women who have obstetric fistula in Ghana¹³, which has identified specific gaps.

“If a woman is referred for fistula surgery, she may need to wait for a year, but no guidance is given as to how to manage the leakage in the interim”

(Health sector humanitarian actor)



GAPS/BARRIERS

The SRH sector, has not yet pro-actively integrated incontinence and its prevention and response, into its work, apart from its efforts to encourage safe births and some concern has been expressed, over including this subject, as one of the SRH sector’s responsibilities. Sometimes understanding on incontinence is limited, either considering it only affects women giving birth, or is only due to fistula. There is an Inter-Agency Working Group on Sexual and Reproductive Health (IAWG SRH) in Crises with a website¹⁴ and chat options and an IWEG SRH Interagency Field Manual¹⁵. Fistula is mentioned

a few times in this manual, but other forms of incontinence are not mentioned. Adolescents are also often an overlooked group in relation to SRH, but are at particular risk of fistula, due to traumatic births. Challenges are also faced with some fistula surgeries, where the surgeons undertaking the operations are not yet sufficiently skilled to undertake the operations. Also, not all fistula services, provide guidance on how to manage residual leakage, or a way to be reintegrated into their communities and families.

Additional findings and conclusions – Health, nursing, midwifery, physiotherapy and occupational therapy services



PROGRESS

Health actors, are already providing some services to people living with incontinence, including, through their care for women and girls during the birthing process. They are providing some services to people living with incontinence, through the provision of stoma bags, in response to conflict-related trauma injuries, and are seeing patients with incontinence resulting from cancer of the prostate, or bladder. In addition, some support has been provided to parents and children, where the children or teenagers have started wetting the bed, due to their traumatic experiences, during war or displacement.



GAPS/BARRIERS

There is often an imbalance between the higher focus put on the medical intervention, or treatment and curative approaches, focusing on the work of medical doctors, instead of focusing on a broader health-care approach. A broader health-care approach, involves multi-disciplinary teams, including nurses, health care assistants, physiotherapists, MPHSS experts and other specialties, including doctors, and has a more balanced focus also on quality of care and dignity. For example, how a person is cared for while in the hospital, the privacy they are given while there to maintain their dignity, how their toileting incontinence needs are supported.

“Actually, very honestly, I don’t have any examples... which basically is the example of how ignorant we are on this subject and don’t “see” these people...”

(Humanitarian health sector actor)

“There is also almost a stigma even in the [health] sector, to deal with incontinence and it is also a taboo subject”.

(Humanitarian health sector actor)

“Older people are mostly invisible to us”

(Humanitarian health sector actor)

Even healthcare providers, including doctors, may not have knowledge on incontinence, from the medical, or health-care perspective. In some countries, there may be some specialized rehabilitation centres for people with spinal cord injuries, but these do not tend to be widespread. Basic advice, from a physiotherapist, which is offered to women giving birth in some higher-income countries, such as advice on doing pelvic floor exercises, is often not available in lower income contexts.

Additional findings and conclusions – Mental health and psychosocial support (MHPSS)

PROGRESS

Some examples exist of MHPSS teams getting involved in incontinence-related issues, including by MSF in Iraq, and St John of God Hospital Services (SJOG), in Malawi, who provide mental health support for half of Malawi. SJOG were involved in the OXFAM-led HIF/ELRHA-funded research, on older people living with incontinence in Malawi¹⁶. The MHPSS focus, was in relation to older people with dementia, and learning about the mental health impacts of living with and caring for someone living with incontinence.

GAPS/BARRIERS

Living with incontinence can lead to severe psychological problems, which might cause anxiety or depression and prevent people from leaving their shelter, to ask for assistance. A number of examples have been shared where people living with incontinence have had suicidal thoughts and people living with incontinence in humanitarian contexts, are known to be at risk of facing abuse and violence from their caregivers. They may also be denied food or drink, to reduce the number of times a person is incontinent. But not very much attention, has been placed on the mental health aspects of this issue so far.

“It can be difficult to have someone help with continence care”

(Humanitarian health sector actor)

“Support to women on incontinence could also improve the mental health of the female population”

(Humanitarian health sector actor)



A home-made urinal for managing incontinence, made from a jerry can, Nguenyyiel Refugee camp, Gambella, Ethiopia

(Credit: M. Farrington/OXFAM/2021)

Additional findings and conclusions – Older persons and disability specialists

PROGRESS

Some of the most sustained engagement in incontinence support to-date, has been by the disability sector actors. Humanity and Inclusion (HI), through learning and practice, over multiple years in multiple country contexts, has developed an internal set of protocols, to guide their support on incontinence for people with spinal cord injuries. Some disability specialist mobile teams exist, which provide tailored support to people living with incontinence and their caregivers, and older-person organisations, such as HelpAge and the Malawi Network of Older Persons Organisations (MANEPO), are also starting to engage more on this issue. Age and disability working groups, exist in some emergencies. A case-control study, covering 1,516 individuals, has been led by the London School of Hygiene and Tropical Medicine (LSHTM) and World Vision in Vanuatu, with other partners, on the menstrual hygiene management (MHM) and incontinence needs of people with disabilities¹⁷.

GAPS/BARRIERS

People with disabilities and older people and their needs, are still often overlooked in humanitarian contexts, across all sectors. Older people living alone, or as an older person couple, may face particular challenges in managing their incontinence and in particular in relation to accessing appropriate WASH services. Older people with dementia and their caregivers, often face more challenges in managing their incontinence, due to the added complications this brings. The person with dementia, may no longer understand how to go to the toilet, as they used to, or know when they need to go to the toilet.

HELPAge AND PARTNERS UNDERTOOK AN ASSESSMENT OF 1,335 OLDER PEOPLE¹⁸ IN COX'S BAZAR CAMPS (2018)

In this study, 17% of respondents, openly admitted that they have incontinence problem and 77% of these respondents, stated that they are struggling and not getting any support. 43% of older people with disabilities who have difficulty getting out of living place, also reported having incontinence.

Additional findings and conclusions – Education and child-friendly spaces

PROGRESS

UNICEF, through their education supply division, have been supporting the innovation of products to support people with disabilities, to be able to manage their incontinence, including in the school environment. Some schools in low- and middle-income contexts (LMICs), have accessible school toilets, although numbers are still low. One of the HIF/ELRHA supported researches, led by the University of Leeds/University of Western Australia, has focused on establishing a participatory tool, based on the Story Book methodology, to encourage groups of children, to discuss their ideas on what it would be like, if a child is living with incontinence in a humanitarian context¹⁹.

GAPS/BARRIERS

It would be positive if the implementation agencies, who are on a daily basis, already supporting children who live with incontinence and their caregivers', can document their learning through this regular engagement; and to ask for recommendations, from people living with this condition, on how the humanitarian community should practically, improve their support practically going forward. It is expected that most children living with more severe forms of incontinence, are not participating in schools or Child-Friendly Spaces (CFSs), so the protection teams, will also need to continue to use their expertise, to reach these children and their caregivers.

Additional findings and conclusions – Camp management, shelter, logistics and supply

PROGRESS

The Shelter Chapter of Sphere, 2018, has mentioned incontinence twice, providing links to the NFI-related guidance, included in the hygiene promotion section, in the WASH Chapter of Sphere²⁰. Work has also been undertaken by WHO and UNICEF, related to assistive aids, including absorbent products and also establishing hygiene kits for people with disabilities / people with special needs kits²¹. The Absorbent Products TAP training is online and UNICEF has sent 38,000, hygiene kits for people

with special needs, to Ukraine. Innovation and learning processes are on-going, led by UNICEF Supply Division. In addition, Loving Humanity²² in Jordan and other locations and World Vision with Mama Laef in Vanuatu²³, have been developing reusable incontinence products and tools. See box below and **Fig 4** – which provides an example of one of the awareness-raising posters, prepared by World Vision and partners, in Vanuatu.

FIG 4 - AWARENESS-RAISING POSTER ON MANAGING INCONTINENCE, WORLD VISION, VANUATU, 2022



RECOMMENDATIONS

Responsibilities and entry points by sector

Following discussions with a wide range of humanitarian actors, to understand possible entry points for engagement with people living with incontinence across sectors, a first attempt has been made to develop an overview image, identifying potential roles and responsibilities. This figure is considered a starting point, to encourage discussion across sectors, going forward. See **Fig 5**.

This figure attempts to identify:

- 1. The main groups of people who are known to live with incontinence** – These are split into three groups – the first group, where incontinence is expected to be widespread; the second group, people with fistula, which is a smaller group of people, but which is the most severe form of incontinence and where specialist support is required, including by GBV professionals; and the third, are groups of people, who are currently invisible to most humanitarian actors.

- 2. Sectoral actors, which have responsibilities to support all groups of people living with incontinence in humanitarian contexts** – This included supporting some groups of people with widespread needs, and others with targeted support.
- 3. Specialist actors, which have responsibilities to support specific groups of people living with incontinence in humanitarian contexts** – through strengthening their existing services.

Overall recommendations

A series of overall recommendations, have been made for: a) NCA – to support its own work; and b) Global humanitarian actors more widely.

NCA, will also need to consider, which contributions, it feels it should also make to global progress,

together with other global humanitarian actors, in addition to, its own humanitarian responses.

Recommendations for NCA

Senior NCA leadership and management commitment, will be essential, to enable incontinence to be fully integrated into the work of NCA. It should be a compulsory component of NCA's humanitarian responses, and should be supported across sectors. It must be a structural requirement and should not just rely on committed individuals to support it, based on their own interests. The efforts to implement these recommendations, should start before the launch of the strategic exercise for planning the new NORAD and NMFA agreements. The overview recommendations for NCA are:

Overview recommendations for NCA:

NCA-R1 – Integrate incontinence support in all WASH, GBV & ASRH humanitarian responses

NCA-R2 – Build awareness and commitment of NCA senior management

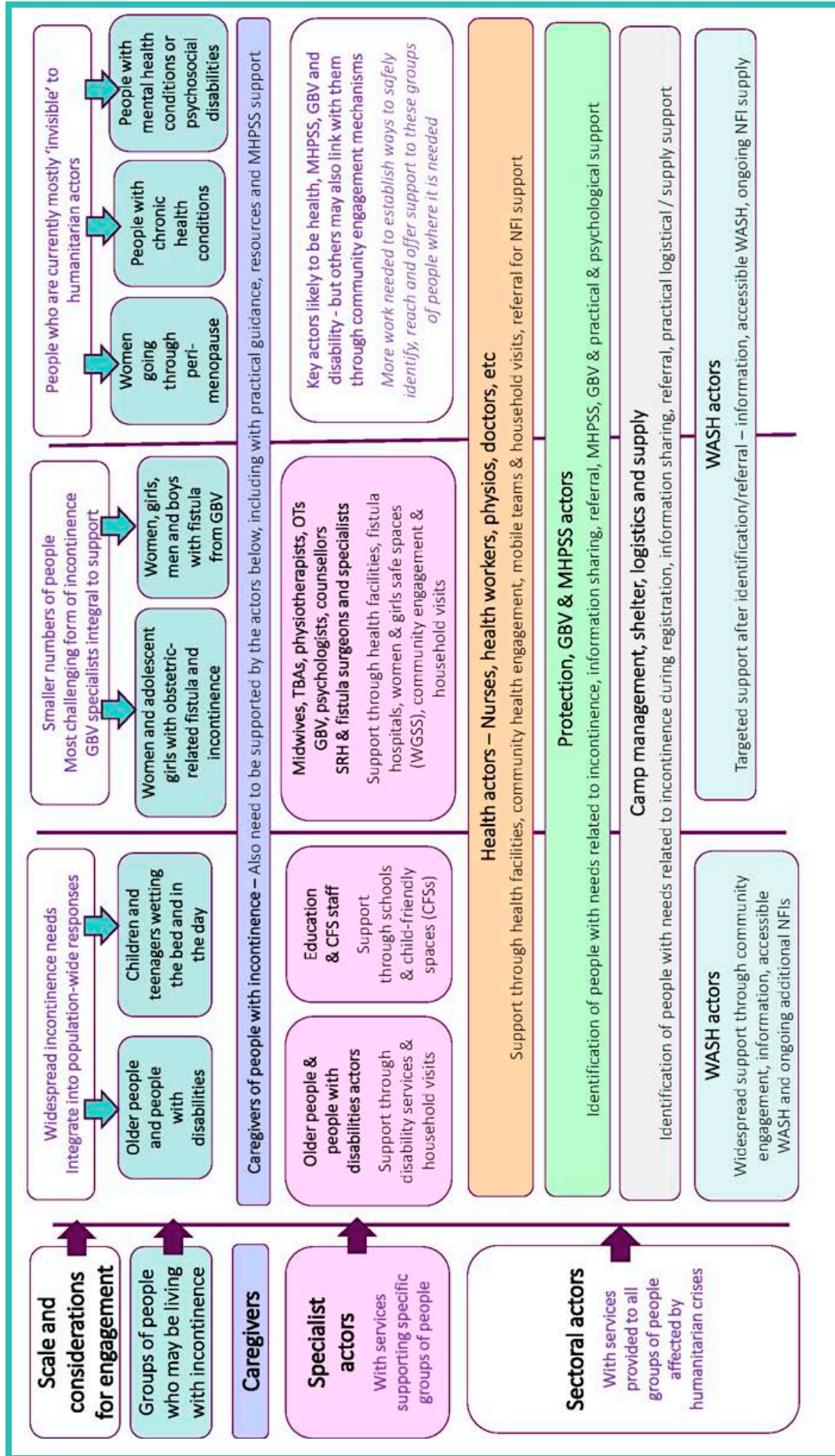
NCA-R3 – Strengthen coordination, planning, baselines and programmes

NCA-R4 – Strengthen budgets and reporting and increase funding for incontinence

NCA-R5 – Develop tools, guidance and training (NCA specific or support global development)

NCA-R6 – Continue to lead by doing and undertake cross-sectoral advocacy

FIG 5 - OVERVIEW ON KEY SECTORAL RESPONSIBILITIES IN PROVIDING SUPPORT FOR INCONTINENCE IN HUMANITARIAN RESPONSES



Recommendations for global humanitarian actors

The following recommendations are made for global humanitarian actors. The first 6 recommendations, apply across all sectors, and 7 to 16, apply to specific sectoral actors.

The NCA recommendations above and the recommendations for the global humanitarian actors, are expanded in **Section 7**. They are supported with additional, more specific practical recommendations, supporting the implementation of the overall recommendations.

Overview recommendations across sectors:

GHA-R1 - Increase awareness and commitment at global Inter-Agency Steering Committee (IASC) and cluster coordination levels, on the cross-sectoral responsibilities to support people living with incontinence in humanitarian contexts

GHA-R2 – Global WASH Cluster / UNICEF, to coordinate and document learning to supporting people with incontinence in the Ukraine response

GHA-R3 – Donors to specify requirements for supporting people with their incontinence

GHA-R4 – Develop standards, assessment and other tools suitable for different users

GHA-R5 - Build capacities of actors across roles, to understand responsibilities related to incontinence

GHA-R6 – Learn from people who live with incontinence in humanitarian contexts, as to their needs

Overview recommendations for specific sectors:

GHA-R7 – In the WASH sector, integrate incontinence into their standard programmes, to improve access to WASH facilities, raise awareness, clarify NFI needs and develop distribution options

GHA-R8 – Raise awareness on the mental health impacts of living with and caring for someone with incontinence and approaches to reduce risks of violence, towards people who live with this condition

GHA-R9 – Utilize existing opportunities within the work of SRH professionals, to reach people who use their services, with information on incontinence and where to go to get support

GHA-R10 – Strengthen collaboration across sectors, to prevent fistula and strengthen care and services, to support fistula survivors to manage their incontinence more effectively and to lead healthy, productive and dignified lives

GHA-R11 – Strengthen the multi-disciplinary team approach, and care and dignity within health services, building capacity of all staff from doctors to support staff, and improve facilities and procedures to support people with incontinence

GHA-R12 – Strengthen capacity and operational procedures, related to midwifery, physiotherapy and occupational health services, to strengthen interventions related to prevention, care and rehabilitation of people living with incontinence

GHA-R13 – Develop approaches for supporting people living with incontinence and their caregivers, with their mental health and to reduce risks of abuse and violence towards people living with it

GHA-R14 – Strengthen understanding, capacities and practical support for older people and people with disabilities (including fistula survivors), in managing their incontinence

GHA-R15 – Build capacity of school and CFS staff and ensure effective access to WASH services for children and staff living with incontinence, who use or work in their services

GHA-R16 – Build capacity of camp management, shelter, logistics and supply staff, to understand their roles related to supporting people with incontinence

Please refer to the Section 7 for more details, learning, explanations, case studies and guidance for the ways forward.

SECTION 2

BACKGROUND

AND MAPPING DESIGN



2.1 NCA

Norwegian Church Aid (NCA) is a faith-based, ecumenical, non-governmental organisation, which works for global justice with communities, in humanitarian contexts and in long-term development contexts, to address the root causes of poverty. NCA works to help the poorest and people in need, regardless of their creed, race, political, or religious affiliation. NCA is also part of the ACT Alliance, one of the world's largest

humanitarian alliances, with organisations across religious faiths, in over 140 countries. NCA's values emphasize that all life has inherent value, which we have a duty to protect and it focusses on ensuring human dignity for everyone, with a particular focus on people who experience poverty, oppression, or exclusion, and in integrating compassion into all of its work.

NCA'S WORK IN HUMANITARIAN CONTEXTS

In humanitarian contexts, NCA largely works in three sectors – Water, Sanitation and Hygiene (WASH), Gender-Based Violence (GBV) and Adolescent Sexual and Reproductive Health (ASRH). Currently, NCA is implementing humanitarian WASH in 13 countries, under the Norwegian Ministry of Foreign Affairs, Strategic Partnership Agreement (NMFA

SPA). This involves work in: Afghanistan, DRC, Ethiopia, Lebanon, Nigeria, Palestine, Sahel (Mali and Burkina Faso), Somalia, South Sudan, Sudan, Syria and Ukraine. NCA also has humanitarian WASH activities funded by other donors in other countries, such as Pakistan.

WHY NCA INITIATED THIS MAPPING PROCESS

In line with NCA's rights-based approach, NCA seeks to strengthen their efforts to reach crisis-affected people who are incontinent. This also aligns to the principles of "leave no one behind" and "do no harm" and is underpinned by NCA's global strategy, *Faith in Action*. Currently, people with incontinence are widely overlooked and hidden in humanitarian responses. Hence, NCA wishes to reflect on its current efforts to integrate support for people living with incontinence and to identify how this aspect of their humanitarian responses can be strengthened. The NMFA SPA period started in 2020 (originally running to 2024). This agreement has included an indicator under the MHM output in the WASH outcome. But whilst some informal practical guidance now available, as a useful starting point, NCA does not feel it has enough capacity, including tools or training, to implement or monitor incontinence activities, with assured quality.

Whilst the main focus of these efforts is under the NCA WASH programme, NCA would like to continue to strengthen its understanding of the linkage between incontinence, its work on WASH, ASRH and GBV, and the programmes and services they provide. There was also a need to better understand the awareness, or gaps in awareness, of the country programme teams, on the need to support people living with incontinence. Without commitment at this level, progress is unlikely to be made. In addition, at the same time, NCA would also like to learn from others, in relation to their experiences, learning and good practices. It is hoped that this could also be used to strengthen its own work; and it hopes will also encourage wider action by other humanitarian actors, to help a wide range of people living with incontinence, to be able to live their lives with dignity.

2.2

Introduction to incontinence in humanitarian contexts

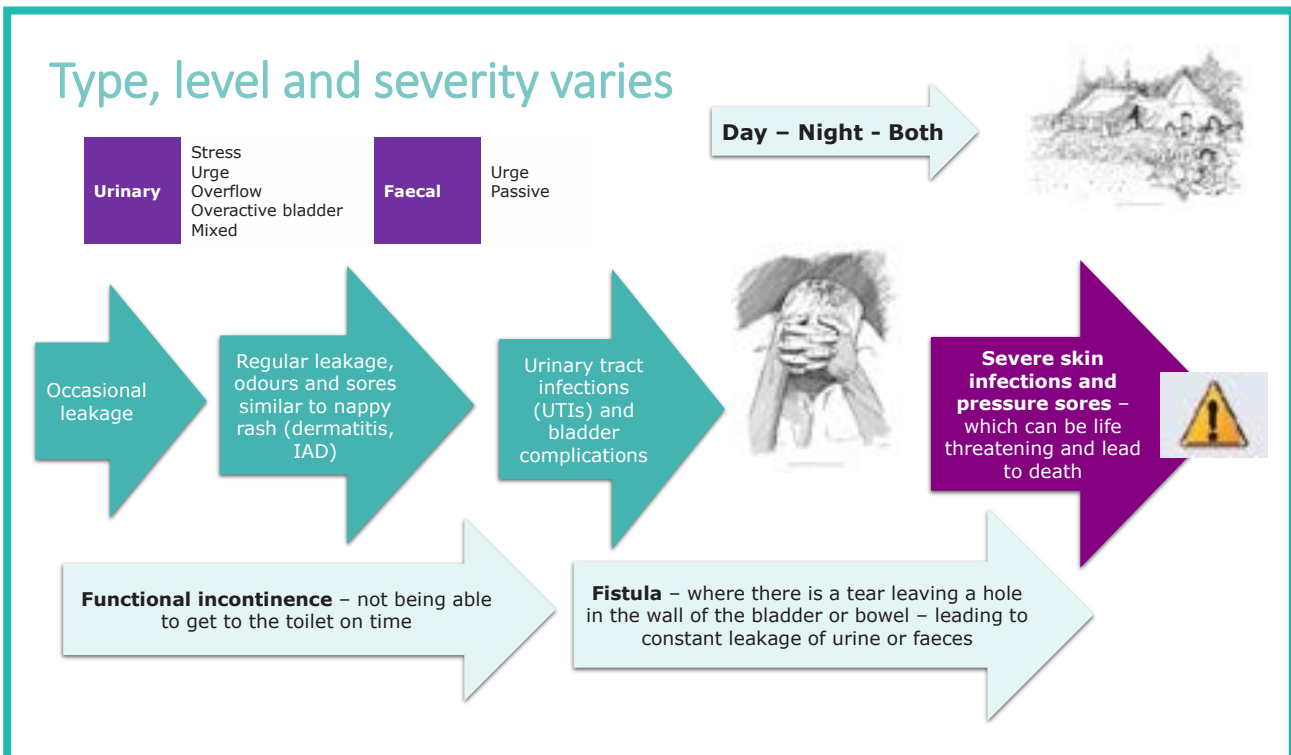
WHAT IS INCONTINENCE?

Incontinence is a condition where an individual is unable to control their bladder and/or bowels, and may leak, either urine, or faeces, or both. It is considered as incontinence when the leakage is not thought of as socially acceptable.²⁴ This mapping process, has not considered the management of babies' faeces, as a child cannot be considered incontinence medically, until they are over 5 years of age²⁵. Toilet training is also considered as part of the normal developmental learning for a young child, and is seen as socially acceptable. However, some of the practical actions supporting people with incontinence, will also be of use in the management of babies' faeces. There are different forms of incontinence. It may be urinary or faecal. For urinary it can be stress, urge, overflow, or a person can have

an overactive bladder, or they may have mixed forms of incontinence. For faecal, it can be urge or passive, where a person does not realize, they are going to the toilet, such as when someone has a spinal cord injury.

Incontinence is a condition which affects many groups of people, but is surrounded by embarrassment and stigma, which means people may be reluctant to talk about it. People can be affected by incontinence in a variety of ways and at different levels of severity. This is indicated in **Fig 6**. But in all forms, managing leakage of urine or faeces onto clothes, seats, or bedding, is very difficult, and can severely affect a person's ability to engage in every-day life and to live with dignity.

FIG 6 - OVERVIEW OF THE RANGE OF TYPE, LEVEL AND SEVERITY OF INCONTINENCE



WHY INTEGRATING INCONTINENCE INTO HUMANITARIAN RESPONSES IS SO IMPORTANT

People living with incontinence can face a range of additional health and social problems, from issues with odour and skin damage, to urinary tract infections (UTIs), bladder complications and Incontinence Associated Dermatitis (IAD) (similar to problems, more commonly known as 'nappy rash' in babies). This is as well as sores (commonly known as pressure sores, or bed sores), which in some cases can become infected and be life-threatening and can even lead to death. These are particularly a problem, for people living with incontinence who are immobile. Therefore, living with incontinence, can potentially have a serious impact on your health. Incontinence, can also have a big impact on mental health and wellbeing, with anxiety and depression being common, due to the significant impact it can have on a person's life.

Easy access to appropriate water, sanitation and hygiene (WASH) facilities, are essential to be able to manage the leakage and contain the odour of urine or faeces, to allow people living with this condition to be able to live with dignity and to be able to engage in daily activities outside of the home. People may also need access to other non-food items (NFIs), such as catheters, with associated urine bags, incontinence/continence pads, mattress protectors and soap and water. This is, as well as needing ability to wash, dry and dispose of incontinence related products. People living with incontinence and their caregivers, also need access to health information, on how to keep healthy and well.

But in humanitarian contexts, where people are on the move, or are living in poorly serviced refugee or IDP camps, access to WASH facilities may be difficult. People may also have limited access to soap and water, as well as privacy, to be able to wash and dry soiled clothes, pads, bedding, or cleaning and drying a urine-soaked mattress. Caregivers of people living with incontinence, may also be severely restricted in their lives and be unable to work, join in community activities, pick up aid items, or if the caregiver is a child, to go to school.

The true scope and scale of the problem is unknown, largely due to the taboo surrounding incontinence, which makes planning for responses difficult. Responsibilities for supporting people with incontinence, also cuts across professions and sectors. For example, WASH, general health, sexual and reproductive health, physiotherapy, gender, GBV, older people and people with disabilities, logistics, etc. Yet, it remains an overlooked issue by most sectors, partly due to the taboo and stigma surrounding the issue and also as sectors can also say, it is not their responsibility, but another sector's responsibility, because responsibilities are not yet clearly defined across sectors.

2.3

Objectives of the mapping process

OBJECTIVES OF THE MAPPING PROCESS

- 1** To map how humanitarian actors globally, are currently engaging with and supporting people living with incontinence, in their humanitarian responses.
- 2** To map to what extent NCA is currently addressing incontinence in its humanitarian responses.
- 3** To provide guidance on how NCA can strengthen the integration of incontinence into its humanitarian responses, with a particular focus on WASH; but also considering GBV and ASRH.

It is also hoped, that the resulting report will encourage other actors to increase their engagement in working with and supporting people with incontinence, living in humanitarian contexts.

2.4 Process

TIMELINE AND RESEARCH TEAM

The mapping process was undertaken between July and December 2022. It was led and guided by Áshild Skare and Peter Cawley, WASH Advisors, for NCA at Head Office (HO). The mapping activities were undertaken by: Dr Sarah House, Independent Water, Sanitation and Hygiene (WASH), Public

Health Engineering & Equality and Non-Discrimination Consultant; and Dr Chris Chatterton – Freelance Medical and Social Researcher, Science Writer/Editor, and Advocate for People Living with Continence Issues.

PRINCIPLES AND ETHICS FOR THE MAPPING PROCESS

The mapping process was undertaken using the following principles:

- ✔ **Understanding the limitations in existing practice** – recognizing this subject is relatively new for most actors
- ✔ **Identification of both good practices and challenges faced by humanitarian actors**
- ✔ **Focus on needs and also what is practical in each context** – trying to be realistic, as to what can be possible
- ✔ **Nothing about us without us** – the consultancy team also brought their own knowledge, from their personal experiences of living with incontinence, to the consultancy
- ✔ **Doing no harm** – care was taken in how information was collected, to encourage openness, and documented to ensure that no harm occurred through the process, through ensuring confidentiality, as preferred by the people sharing their experiences

METHODOLOGY, APPROACHES

The mapping was undertaken using the following methodologies:

- Introductory webinar with NCA staff (WASH; GBV; ASRH)
- Online survey with NCA staff (WASH; GBV; ASRH)
- Desk study
- Key informant interviews (KIIs) and focus group discussions (FGDs), undertaken with NCA teams and global humanitarian actors (GHA) working on incontinence

ACTIVITIES AND CONTRIBUTORS

Contributors participated in this process, through their engagement in the NCA webinar, in the NCA online survey, or through being interviewed in KIIs (one or two participants), or in FGDs (three or more participants) per activity. A range of other

participants contributed through establishing linkages to colleagues for interviews, sharing information by email, through sharing documents, or through checking organisational entries.



PARTICIPANTS IN THE NCA WEBINAR

- 25 NCA staff and partners participated in the webinar – WASH, GBV and ASRH



PARTICIPANTS IN THE NCA ONLINE SURVEY

- 18 NCA staff and partners (13m/5f) participated in the online survey – 22% were in 18-30; and 78% in 31–50-year age-bracket
- Of the participants, 67% work in WASH; 17% in ASRH and 17% in GBV (could only answer for one option, but some participants work in GBV, as well as ASRH)
- Participants were working in the following regions of the world – 61% Africa; 17% Asia; 6% Middle East; 11% HO; and one stated as 'other'
- Participants who shared their country location (question was optional) – were in Mali, Afghanistan, Bangladesh, DRC, Ethiopia, Mali/Burkina Faso, Somalia, Syria/Lebanon, HO



PARTICIPANTS IN THE KIIS AND FGDS – NCA AND OTHER GLOBAL HUMANITARIAN ACTORS

- 53 people (21m/32f) participated in 39 KIIs and 2 FGDS
- Interviewees represented 23 agencies or institutions - 5 UN and IOM; 12 Faith Based Organisations (FBOs) and Non-governmental Organisations (NGOs); 3 universities; 1 foundation; 1 federation; 1 private institution
- Representatives, mainly work in the following sectoral areas (some work in more than one) - WASH – 25; Health – 13; Disability – 12; GBV or protection – 6; ASRH – 5; Innovation/Supply/NFIs/Assistive Aids – 4; Management – 1.
- Participants are currently working in the following countries - Afghanistan – 2; Bangladesh – 1; DRC – 3; Ethiopia – 1; Ghana – 1; Lebanon and Syria – 3; Somalia – 1; South Sudan – 1; Ukraine – 3; Vanuatu – 1; Head Office (HO) – 33; Universities – 3; Independents – 1

Note that a few participants, were involved in two or three of the activities (webinar, online survey and KII or FGD) and have been double, or in a few cases, triple-counted above.

Refer to **Annex I** - for a list of contributors to the process.

CORE MAPPING QUESTIONS

The core mapping questions to be answered, were as follows:

CORE MAPPING QUESTIONS

LEARNING FROM OTHER ACTORS:

- | | |
|---|---|
| <p>1. Which humanitarian actors, are currently working on incontinence in their responses and how are they doing this?</p> | <p>2. What successes and challenges have been experienced and how have they responded?</p> |
| <p>3. Which other supporting activities have been undertaken, which are also useful for implementing agencies, for example, product development, supply, research, or other areas?</p> | <p>4. What recommendations do other actors make, for what is needed going forward?</p> |

NCA'S ENGAGEMENT TO-DATE:

- | | |
|---|--|
| <p>5. How is the NCA currently addressing incontinence in its programmes?</p> | <p>6. When did this engagement happen, where, for how long, and what was the scale?</p> |
| <p>7. What was the result and was feedback sought on the intervention, or a review undertaken?</p> | <p>8. What are the barriers to the NCA teams engaging with this topic?</p> |

HOW CAN THE NCA STRENGTHEN THEIR WORK GOING FORWARD:

- | | |
|---|--|
| <p>9. How can the NCA strengthen the integration of incontinence in their humanitarian responses?</p> | <p>10. At what stage in the humanitarian process, should the NCA start engaging with incontinence?</p> |
| <p>11. How should the NCA priority sectors of WASH, GBV and ASRH, link in with and collaborate in responding to incontinence in humanitarian contexts?</p> | <p>12. What will be needed to help the NCA engage practically (i.e., what recommendations, tools, guidelines will be needed)?</p> |

CHALLENGES AND LIMITATIONS

The main challenges of this mapping process included: how to reach a range of people working across sectors and in multiple country contexts and to encourage them to share their experiences and challenges honestly; how to encourage people who have not engaged to far, to share the barriers which are preventing them doing so, and ideas for what would be needed going forward, to help them engage.

The main limitations were that incontinence is known to be a relatively new subject being discussed and acted upon, in the global humanitarian and development communities, and hence it was not clear how easy it would be to find examples of action on the ground. In addition, whilst 53 people were involved in the interviews and 18 in the online survey, across a range of different kinds of institutions, and

country contexts, and a few of whom had in the past worked in governmental roles, none of the participants currently work for government institutions. This is a gap, that would also be interesting to investigate further going forward – how are government institutions considering and responding to this issue?

To overcome some of these challenges and limitations, effort was made to design the mapping process to acknowledge the limitations in existing knowledge and practice and to encourage openness in sharing. Contacts for interviewees, were initially made through the NCA teams and through members of the global informal email group on incontinence in low and middle income and humanitarian contexts, and specific efforts made to reach and where possible, to involve people working in the field across country contexts.

SECTION 3

FINDINGS – LIVING WITH INCONTINENCE



3.1

People affected by incontinence

A wide range of people may struggle with living with incontinence. The following groups of people, who practitioners have met in humanitarian and low- and middle-income contexts, have been living with incontinence. This section describes the types of challenges that each group may face and then

highlights some of the work globally, which has been happening to learn about or support each group of people. It is hoped that these examples, will then encourage the readers, to look at other sections, to read about this work in more detail.

OLDER PEOPLE

As people get older, their pelvic floor muscles may become weaker, they may have increasing numbers of chronic health conditions, some may get dementia, they may face challenges such as prolapses in their gynae-urological areas. They may also become less mobile on their feet, and hence not be able to get to a toilet on time. All of these can lead to an increase in incontinence.

OLDER PEOPLE AFFECTED BY JAPAN EARTHQUAKE AND TSUNAMI

HelpAge undertook a study of the situation of older people during the response to the Great East Japan Earthquake and Tsunami in 2011. The older people faced many challenges, including related to their WASH needs (p3, 9, 11) and in accessing incontinence materials (p18). <https://reliefweb.int/report/japan/displacement-and-older-people-case-great-east-japan-earthquake-and-tsunami-2011>

EXAMPLES OF RESPONSE OR SUPPORTING ACTIVITIES

International discussion between agencies on people living with incontinence in humanitarian and LMICs, was initiated following pro-active actions being taken by NCA to support older people with their incontinence, living in humanitarian contexts in Liberia, Lebanon, Iraq and Tanzania. NCA has also provided additional cash transfers, as a pilot for vulnerable households, some of which have household members with incontinence, in South Sudan. Particular attention has been placed on supporting older people living with incontinence in the Ukraine humanitarian response, with leadership by the WASH Cluster leadership in Ukraine. Interesting examples exist of the work in Ukraine, for example, by the NRC. They have provided incontinence support to older people living in bomb shelters, in collective centers and in care homes. NCA and partners HEKS-EPER and DCA, are also in the planning phase for distributions to older people living with incontinence in Ukraine. A research study led by OXFAM and HelpAge and involving a range of partners, funded by the Humanitarian Innovation Fund (HIF) of ELRHA, focused on the situation of older people living in post-cyclone affected, Malawi and in refugee camps in Gambella, Ethiopia.



A child's drawing on how a child would feel when they have wet themselves – process facilitated using the participatory Story Book methodology, Adjumani District: Adjumani Refugee Settlement, Uganda

(Credit: Uganda Christian University / February 2022)

CHILDREN/TEENAGERS

(excluding children below 5). A child is also not considered to be able to have incontinence medically, until they are over 5-years of age. However, as children become older, when children revert to not being able to control their urine or faeces, this then becomes socially-unacceptable and poses bigger challenges for mental health and management.

Multiple examples of children and teenagers wetting the bed – and their caregivers seeking support for

its management – were shared, particularly from conflict zones and displacement situations, where children had fled conflict, or had traumatic journeys, such as travelling by small boats, across rough seas. This highlighted the impact of trauma of conflict, or other stressful experiences, on the presence of incontinence in children in humanitarian situations²⁶. Children may also urinate and/or defecate on themselves, because they are not able, or do not want, to use the sanitation facilities available.

EXAMPLES OF RESPONSE OR SUPPORTING ACTIVITIES

Examples were highlighted of responses implemented by the IRC, the IFRC and MSF, to support children who wet the bed and their caregivers, from the Regional Syria Response, from Iraq and from Greece and Honduras. Examples included, increased resources for washing and cleaning sheets, phone lines to request care, and psychosocial support for parents, teaching them how to support their children to stop bed-wetting. Leeds University/The University of Western Australia and partners, also led a research study, funded by ELRHA/HIF, to develop a 'Story Book' methodology, to facilitate discussions with groups of children to explore the possible experiences of children if they self-wet (wet themselves)²⁷. This research was undertaken in Bangladesh and Uganda.

WOMEN AND GIRLS - OBSTETRIC-RELATED

A range of incontinence-related challenges can occur, in relation to complications during the process of child-birth. Where women and girls face obstructed or prolonged labour, they may face the risk of obstetric fistula, where an abnormal hole occurs between the vagina and the bladder, and, or rectum, causing urine or faeces or both, to constantly leak from their bodies. In addition, even

if the woman or girl has had an operation to repair their fistula, they may also face other damage to their pelvic floor, or have a prolapse, where the womb or bladder become misplaced. These can also lead to other forms of incontinence. Girls and young women, who face early marriages, or have babies before their bodies are fully formed, are more at risk of obstetric fistula.

“I was shattered. I felt confused. I had just finished learning to sew, about to open my own business and this thing just happened to me. Life has been very difficult from the moment”

Woman who with interviewed in relation to living with fistula. Quote documented by Research and Grant Institute of Ghana/2021 Ghana

EXAMPLES OF RESPONSE OR SUPPORTING ACTIVITIES

A number of organisations, such as the Fistula Foundation, UNFPA, NCA, MSF, and HI, have supported women who have obstetric fistula, in a range of countries and contexts, including in humanitarian contexts, such as DRC, Ethiopia, northern Nigeria, Somalia and Tanzania. The Hope Hospital in Cox's Bazar, Bangladesh, also supports women who suffer with fistula, including from the Rohingya communities, living in camps and communities in Bangladesh. The Panzi Hospital in Bukavu, supports women and girls affected by fistula. NCA provides GBV training for the hospital staff and have also improved the WASH facilities at the hospital. The Research and Grants Institute of Ghana and partners, also led a research study, funded by ELRHA/HIF, on the WASH needs of women living with obstetric fistula in Ghana.

WOMEN, MEN, GIRLS AND BOYS AFFECTED BY GBV

Women, girls, men and boys, can also face fistula from serious sexual assault, such as rape. Fistula due to any reason, is a devastating condition to have, and is incredibly difficult to live with. It can lead to abuse and rejection by family members, leading to isolation and severe

mental health challenges. Fistula due to serious sexual assault, also poses additional levels of challenge for the people affected, due to the stigma and trauma, of both the fistula as well as the GBV and sexual assault.

EXAMPLES OF RESPONSE OR SUPPORTING ACTIVITIES

A number of organisations, such as the Fistula Foundation, UNFPA, MSF and NCA, work with, or support fistula hospitals in DRC, where there is a high level of sexual violence and hence many fistulas occur. Examples, were also shared from Kenya, from government supported hospitals, who provided support to women affected by serious sexual assault (rape), during post-election violence²⁸.

WOMEN AND GIRLS WHO HAVE UNDERGONE FGM

The issue of fistula, is also a major challenge for women and girls in Somalia and other countries, where female genital mutilation (FGM) is still practiced. In the most severe form of FGM/C, known as infibulation (Type III), all of a woman or girl's genitals are cut away and the hole is stitched up, apart from a very small hole, to allow out urine and menstrual blood. Each time the woman or girl gives birth, the wound is ripped open. Women and girls are then stitched up again, for the process to be repeated, during the next birth. The link between FGM and fistula is still a bit controversial. WHO states, '**A direct association between FGM and obstetric fistula, has not been**

established. However, given the causal relationship between prolonged and obstructed labour and fistula, and the fact that FGM is also associated with prolonged and obstructed labour, it is reasonable to presume that both conditions could be linked in women living with FGM²⁹. A review of the potential links between FGM and fistula was analyzed from a number of studies, in 2017. This review concluded: '**The risk of developing fistula, appears to rise with the severity of the FGM/C cut, particularly Type III³⁰.** For further discussion, see **Section 5.2.1** and case study, **CS-GHA-H – in Supporting document 1.**

EXAMPLES OF RESPONSE OR SUPPORTING ACTIVITIES

Both MSF and NCA have some activities, or have provided funding, to support fistula care in Somalia, where FGM is common.

PEOPLE WITH DISABILITIES

People with a range of disabilities, may also face different forms of incontinence. For example, some people may struggle with functional incontinence, where they cannot get to the toilet in time, if it is too far away from their house or bed. People with spinal cord injuries (SCIs), may not have any control over their bladder and bowel function, and

may benefit from the use of catheters, to manage their urination, although these also pose some challenges. Some people with mental health conditions and psychosocial disabilities, such as some people with learning disabilities, or dementia, may also face difficulties in knowing when to go to the toilet.

EXAMPLES OF RESPONSE OR SUPPORTING ACTIVITIES

Humanity and Inclusion, CBM and World Vision, all engage with people with disabilities in humanitarian and low-income country contexts and have provided a range of incontinence-related support. Examples of practical actions supporting people with disabilities, were shared by Humanity and Inclusion (HI) from South-East Asia, Ukraine, Haiti and elsewhere. UNICEF has also sent 38,000 hygiene kits to Ukraine, with specific items of relevance to incontinence. The kits are known in Ukraine as hygiene kits for 'People with Special Needs' (PSN), and known at global level, as kits for people with disabilities. NRC has also supported care homes for people with disabilities, with materials to manage hygiene and incontinence. A large scale-study has also been undertaken in Vanuatu, led by the London School of Hygiene and Tropical Medicine (LSHTM) & World Vision and partners, comparing the situation of people with disabilities and people without disabilities, in living with and managing their incontinence and menstrual hygiene. World Vision and partners, have continued, in response to findings of the research, with trials of practical support for people with disabilities, to help them manage their incontinence. World Vision and CBM, working in Sri Lanka, have also prepared some excellent practical guidance documents, on supporting people with additional hygiene needs. This includes guidance on supporting people with incontinence and HI has developed protocols and an internal toolkit, supporting people with spinal cord injuries.

PEOPLE WITH CHRONIC OR ACUTE ILLNESSES

People with a range of different types of chronic illnesses, may also may face incontinence, due to the effect of the illness, on the functioning of the structures or systems, controlling their urinary or feecal systems. In addition, men with prostate cancer and males and females with bladder cancer, who have incontinence, have also been met in MSF clinics. In addition, to these specific examples shared by the humanitarian respondents, a range of other people with chronic illnesses, who are

also likely to be present in humanitarian contexts, may also live with incontinence. This might include people living with asthma, people who live with chronic coughs, people with neurological conditions, or immune system conditions (such as Multiple Sclerosis), or connective tissue disorders (such as Ehlers-Danlos Syndrome). Men who have had prostate surgery, and also people living with epilepsy, may also face incontinence, during their epileptic seizures. People who have had strokes, may also lose control of their bladder or bowel, depending on the severity of the condition and which part of their brain has been affected. In addition, people who abuse drugs and alcohol, which is considered a mental health condition by WHO, may also face incontinence, due to losing control of their bodily functions.

'A lot of people in Vanuatu have diabetes, but were not told that diabetes can lead to incontinence. Many thought it is just part of ageing.'

(Finding from Vanuatu study on MHM and incontinence focussing on people with disabilities, by LSHTM and World Vision, 2019)

WOMEN GOING THROUGH THE MENOPAUSE

A high proportion of women, it is estimated, even one or two women out of every three, going through the peri-menopause, or menopause process, will face incontinence. The menopause process, is the process where a women's periods eventually stop. The whole process, can lead to significant changes in a women's life and health. They may face many symptoms, including incontinence, with the change process happening over a period of 10-

15 years, and some symptoms remaining longer-term. These are due to changes in the production of the hormones, estrogen, progesterone and testosterone. Hence, many women, often between the ages of 40 to 55, and sometimes younger or older, in humanitarian contexts, may also be struggling with the menopause process, including incontinence.

EXAMPLES OF RESPONSE OR SUPPORTING ACTIVITIES

As far as we could determine, no specific activities, have been undertaken in humanitarian contexts, supporting women going through the menopause process, to manage their incontinence. Women going through the perimenopause process, are often invisible, even to medical professionals in many parts of the world, including higher-income country contexts. Some efforts, have however, been made on the side of research. Amita Bhakta, undertook her PhD at WEDC in Loughborough University, on the WASH needs of peri-menopausal women living in Ghana and has subsequently, also developed a one-day training course on the same. This was a lower-income country focused-study, rather than humanitarian focused, but all women, in all contexts, who live into their 50s, will have gone through the menopause process. A plan is in process, to develop a briefing note on practical actions, which can be undertaken to support the WASH needs of women going through the menopause process.

MEN LIVING WITH INCONTINENCE

A specific note is also being included here, to highlight that men also struggle with incontinence. They may already be included in the groups of people highlighted above, and may face conditions such as stress incontinence. They may face problems with their pelvic floor, face incontinence after a prostate cancer operation, have incontinence due to stroke, or having a spinal cord injury, or due to the

psychological impacts of the trauma of conflict, or overuse of alcohol, or drugs. In addition, men who don't have a regular problem with incontinence, may also face the occasional accident. The stigma for men, is felt to be even more challenging; so, seeking help for managing their condition, may also be even more challenging.

3.2

Humanitarian contexts

Humanitarian contexts vary significantly, each of which poses its own challenges on the management of, and support for people living with incontinence. The following humanitarian contexts were described, where practical incontinence support, has already been provided.

PEOPLE ON THE MOVE

People on the move managing their incontinence, face particular challenges from having limited access to water and sanitation and to privacy and limitations in what they can carry while moving.

EXAMPLES OF RESPONSE OR SUPPORTING ACTIVITIES

The IRC, provided hygiene support for people on the move, in the European refugee crisis, as people were arriving in Greece after long sea crossings. This involved using hygiene hubs (tables with a range of hygiene products on), for people to see what is available and to select and take the items they needed for their journeys, including incontinence pads.

PEOPLE REMAINING IN THEIR OWN HOUSES

Older people are most likely to remain behind in their own houses, when younger and fitter adults and children, migrate to escape natural disasters, or conflicts.

EXAMPLES OF RESPONSE OR SUPPORTING ACTIVITIES

In Ukraine, during both the Crimea humanitarian emergency and the current conflict, the majority of people who have remained in their own houses on the frontline, have been older people; either not wanting to leave, or not knowing where they would move to. Some have been provided with support, such as toilet chairs, pads and other hygiene items, to help manage their incontinence, while living alone and when the availability of products is lacking in local stores.

PEOPLE IN BOMB SHELTERS / BASEMENTS

In the middle of ongoing conflicts, people may move to basements and underground bomb shelters or other locations, such as underground tube stations. In these locations, people may have limited, or no access to functioning toilets and limited ability to wash, clean and dry themselves and their clothes and bedding. When non-food distributions are provided, there may be limited opportunity for the distributing teams to visit the underground locations, or to ask the people in them questions. Hence, distributions, may need to be mass distributions, rather than targeted.

PEOPLE IN COLLECTIVE CENTRES

People staying in collective centres, are where buildings such as schools, community or sports centres, or other locations, are adapted to allow people who are displaced to stay in a place of safety, usually as a temporary measure. Here mattresses may be set up in close proximity for large numbers of people to sleep on. Such centres, pose different

challenges for the management of incontinence. In such centers, privacy may be lacking with large numbers of people staying close to each other, with limited privacy. There may also be large numbers of people, using limited toilets and bathing facilities, and with challenges for managing the washing and drying of clothes, bedding or wet mattresses.

PEOPLE IN CARE HOMES

The staff supporting people living in care homes, such as older people or people with disabilities, are likely to already have experience of supporting their residents with incontinence, which is helpful for its management. But they may lose access to funding or supplies. The challenges found in care homes in Ukraine, has mainly been that they no longer have adequate resources to purchase the non-food

items they require, to support residents with their incontinence, or their supply chains may have been disrupted, particularly if they are near the front-line. They may also have large numbers of people living with incontinence, and hence have requirements for significant numbers of bed protectors, incontinence pads, soap, washing powder, and other cleaning products.

EXAMPLES OF RESPONSE OR SUPPORTING ACTIVITIES

NRC has been supporting care homes in Ukraine with incontinence-related products.

PEOPLE IN IDP OR REFUGEE CAMPS

People living in IDP or refugee camps, are more likely to have their own family shelter and space, than people living in a collective centre. But there are often quite a few people living in the same shelter and hence limited privacy for people living with incontinence to ensure their dignity. In many IDP or refugee camps, it can be common that people only have access to communal latrines,

or bathing facilities, which may not provide much privacy and not be segregated by gender, not be fully accessible, and which may be some distance from the person's shelter. The facilities in most situations, are also still not lit at night and people may not have adequate access to soap, water, or water containers, to be able to manage their incontinence.

EXAMPLES OF RESPONSE OR SUPPORTING ACTIVITIES

UNHCR protection team, has been providing incontinence pads for people with disabilities in refugee camps for the Regional Syria Response. Loving Humanity, is a small charity, which is supporting the production of disposable and washable products for the management of menstrual hygiene and incontinence, for use by people affected by humanitarian contexts. They started producing washable babies' nappies and incontinence products for adults, after hearing how big the problem was in Za'atari refugee camp in Jordan, in 2014.

IDPS LIVING IN COMMUNITIES WITH HOST FAMILIES OR RENTING ACCOMMODATION

People living with host community families, or renting their own accommodation, may have more privacy to manage their incontinence, but

this depends on their specific situation. Managing incontinence within a host family's home, may also cause embarrassment and feelings of shame.

PEOPLE USING HEALTH FACILITIES

People who are living in their own homes, but in areas affected by chronic or cyclic disasters and people who have been displaced into camps, may have to walk long distances to access health facilities. Women and girls may also have to walk long distances to give birth in a health facility and people with a range of chronic health facilities may also need to access health facilities. However, the facilities may not have adequate numbers of accessible toilets for patient use, or provide access

to adequate volumes of water. They may also not provide soap. People may also find it difficult to sit or stand in queues, for long periods of time. Staff, including health staff, may not be fully aware of the challenges for people, who are living with incontinence, when visiting their health facilities. People who soil their beds, when in-patients may also have limited privacy, and mattresses which are not covered in a waterproof layer, may also be soiled.

EXAMPLES OF RESPONSE OR SUPPORTING ACTIVITIES

Médecins sans Frontières (MSF) has been working to improve the way they support people with incontinence, who are using their health facilities in their humanitarian responses, and have added a number of incontinence products into their medical supply catalogue.



Vendors for a humanitarian e-Voucher cash distribution scheme off-loading items for sale, South Sudan

(Credit: Bereket Seifu / NCA / 2021)

PASTORALIST COMMUNITIES

Pastoralist communities often live in dryland areas, which are prone to cyclic droughts, which push the communities to migrate longer distances in drought years. In Somalia, pastoralist communities may also be displaced due to clan-based violence. In other country contexts, conflicts may also occur between pastoralist and farming communities. People in pastoral communities living with incontinence, may already face many

difficulties in managing their incontinence, due to less access to water and items such as pads or other materials, even before displacement. Some pastoral communities, also traditionally managed menstruation, by the girl or woman, sitting on a hole in the ground, into which the menstrual blood would soak. Traditional methods for the management of incontinence in pastoral communities are not known.

EXAMPLES OF RESPONSE OR SUPPORTING ACTIVITIES

NCA has been providing support for pastoral and other communities, to have safer access to water sources, to prevent the risk of inter-clan and inter-community conflicts. Having easier access to water supplies, will be of benefit to help people living with incontinence.

PEOPLE LIVING IN CHALLENGING LOCATIONS WHERE ACCESS IS DIFFICULT DUE TO CONFLICT OR REMOTENESS

The photo below, provides a reminder that in some locations, access can be difficult to provide basic humanitarian support, due to logistic or security

challenges. This adds challenges, to providing logistical support for supplies, for people living with incontinence.

EXAMPLES OF RESPONSE OR SUPPORTING ACTIVITIES

This picture shows NFIs being unloaded by vendors, who are part of a hygiene NFI e-Voucher cash transfer scheme for refugees and host communities in South Sudan, in a pilot for particularly vulnerable households, which include people living with incontinence.

3.3

Challenges of living with incontinence

The following practical challenges and implications for people living with incontinence, were highlighted through the mapping process.

3.3.1

Practical challenges to managing incontinence

How easy it is to manage incontinence, when living in humanitarian contexts, will vary depending on the type and severity of the leakage, the ability of the individual to manage it, and also the facilities and resources the household has access to.

HAVING ADEQUATE CHANGES OF CLOTHES AND BEDDING

If a person is leaking urine or faeces, multiple times a day or night, or it is constantly flowing out of them, because they have a fistula tear, or they have no control over their bladder and bowel, due to a spinal cord injury, then having adequate changes of clothes and bedding will be very important. But when people are on the move, they often are not able to carry many possessions, so they may turn up with only the clothes they are wearing and no bedding. When soiling of clothes or bedding is a regular problem, the whole cycle, of washing and drying and having access to alternative items to use while this is happening, will be essential. But this challenge is not always considered, when NFIs are provided for people affected by humanitarian crises and people arrive in a new destination.

The figure below, highlights how WASH challenges are multiplied, when people are on the move, or living in humanitarian contexts, such as camps or communal centres. Managing incontinence is already difficult and time consuming in higher-income contexts and when having access to adequate water, soap, privacy and washing and toilet facilities. When access to these is no longer available, and privacy is reduced, the management of incontinence is much more difficult.



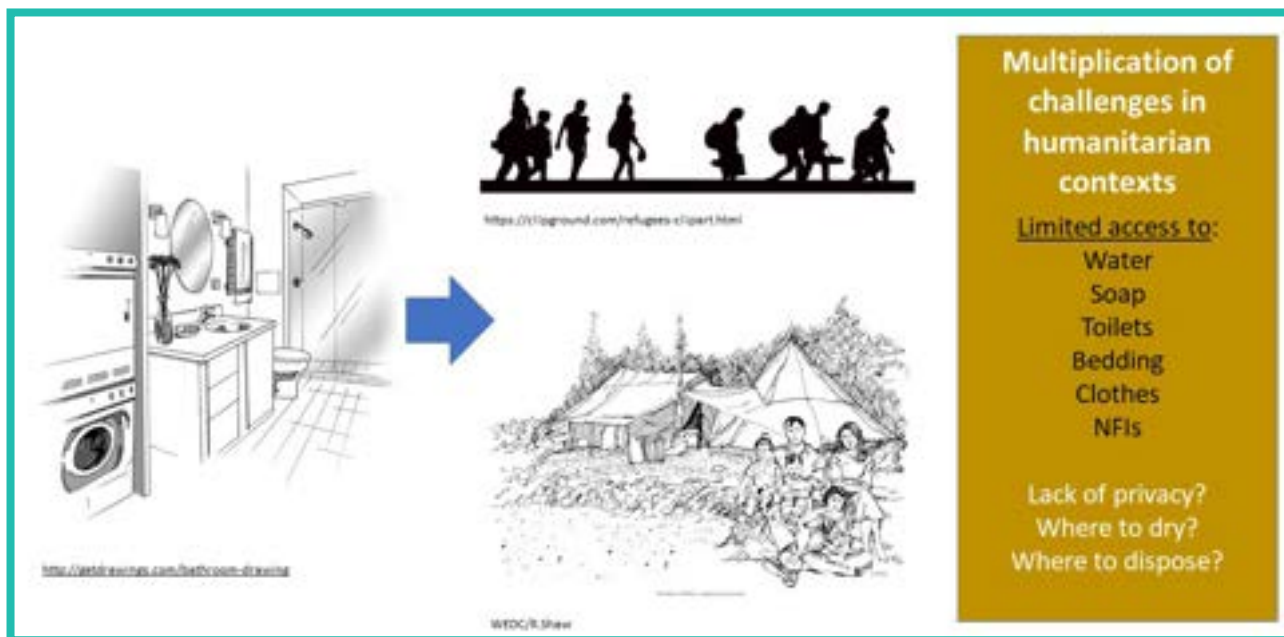
A home-made urinal for managing incontinence, made from a jerry can, Nguenyyiel Refugee camp, Gambella, Ethiopia

(Credit: M. Farrington/OXFAM/2021)

“As we were talking to a woman and her carer, another woman heard us talking about toilets and came out and wanted to talk about her husband who was injured and has a spinal injury. She said that he urinates in the bed and it is very difficult. She wanted to speak as they need help”.

(WASH sector actor, Rohingya camps, Bangladesh, 2019)

FIG 7 - ADDITIONAL CHALLENGES OF MANAGING INCONTINENCE IN HUMANITARIAN CONTEXTS



ACCESSING MATERIALS, WATER AND SOAP

Regular washing of a person’s body and washing multiple sets of clothes or bedding, which need changing, sometimes multiple times during the day or night, requires much more water and soap. One estimation, is that the need can be up to five times as much water and soap for people with severer forms of incontinence. Just providing a household with the basic supplies of soap and only one or two water containers, will not be enough. People may end up selling their food rations, or other items, to be able to afford more soap to be able to keep hygienic, or buying incontinence pads.

If a person needs some form of material to soak up the urine or faeces, such as cloth or incontinence pads, with barrier cream, to reduce the risk of rashes, accessing these and in adequate numbers and in a sustainable way, can also be very challenging. These materials, also need to be of the correct size, and absorbency, and for some the user will also need underwear, which pulls the incontinence pads close to the body, to reduce the risks of leakage.

In addition, if a mattress becomes wet from urine or faeces, this poses significant challenges for people living in displaced situations, whether a collective centre, or an IDP or refugee camp. This can add stress and embarrassment for the person themselves and for their caregivers and other family members. It can also lead to domestic abuse. See below for more information.

If an older person, or an older couple are living alone, they may also not be able to reach the toilet, or to be able to empty and manage buckets used in the house for going to the toilet. Likewise, they may find it difficult to walk to, queue up to collect, and carry back adequate volumes of water. For example, in the Rohingya camps in Bangladesh, the camps are located in a hilly area, and water points may be down a steep hill from the shelters, where people are living.

WASHING, DRYING, DISPOSAL

The person or household will also need to have somewhere to wash and dry clothes, bedding and washable/reusable cloths or pads, and an ability to do this without embarrassment, including when hanging wet items to dry. In addition, if disposable pads are utilized, there is also a need for a disposal system, in which the household can discretely dispose of soiled incontinence materials, as well as faeces and urine, if this is collected in a bucket, such as under a moveable chair used in the house. For the latter, the urine and faeces can be disposed of in a latrine, although it may cause some embarrassment to take such a bucket there for disposal. In most humanitarian contexts, the solid waste systems are still weak and pose significant challenges; with weak or sometimes non-existent collection systems and poor end disposal practices.

PRIVACY

People living with incontinence, also need privacy to manage it, which can be very difficult in collective centres, or even in household shelters, where the space is small and there are multiple family members. The lack of privacy to manage incontinence, can lead to embarrassment, domestic abuse and mental health challenges, for the persons living with this condition and their caregivers.

“We came across a house which had a pathway installed to a latrine for a young man in a wheel-chair... but the latrine was tiny, and the man clearly couldn’t use it alone. His father also said that he has mental disability as well, so that he doesn’t actually know when he needs the toilet, and regularly soils himself. On the ground along the path to the latrine were piles of soiled clothes, which the family had dumped outside as they didn’t have enough water to wash them, and couldn’t keep them in the house for the smell. I’ve asked our team to check in with the house on a regular basis to see what else they might need (soap or larger water storage containers), but it was sad to see that whoever had done the ramp, didn’t think all the way through the other implications that the family were facing”.

(WASH sector actor, Rohingya camps, Bangladesh, 2019)

In an update in 2022, a visit was made by the Global Advisor for the organisation who shared this case study, to the house of this family. She was delighted to see that their team had made modifications to the path and the toilet. A handrail was installed along the path and a fold down seat and handrail was placed over the toilet, both of which mean that the boy can now get to and use the toilet independently, when he needs to. What a difference this little extra thought and action are making to the life of this child and his parents.

FINDING OUT HOW TO ACCESS HELP AND SUPPORT

It is also difficult for people living with incontinence and their caregivers, to know where to go for support, with living with this condition. Who can families ask for extra soap, for extra water containers, for extra bedding, for the incontinence pads, or for help with carrying the extra water needed to manage this condition, when the household themselves are not able to carry such a volume of water per day? This

includes finding out where to go for health support, as discussions through this mapping process, have also indicated that not all health staff have knowledge on this issue, on how it should be treated, or how it can be managed on a daily basis. Findings from a study on the WASH needs of women with obstetric fistula in Ghana, highlighted how no education or support, is often not even given to women with fistula.

This finding was also confirmed from other mapping respondents, who also stated that this is also common in other country contexts. One respondent shared, that they may refer someone to a fistula hospital, but the referred person, may not be able to have the operation for more than a year, as they need to wait for an international surgeon to arrive, to undertake large numbers of operations at the same time. But in the meantime, no guidance is given to how to cope with the constant flow of urine or faeces. And likewise, when women have had the fistula operation, they may also be sent home, without practical WASH and hygiene guidance, even if they still have other forms of incontinence, which is quite common.

Some people may also need more technical support for the supply and insertion and removal of catheters, so that they do not have a constant flow of urine. This includes for people with spinal cord injuries, or after an operation, including a fistula operation, while the surgery is healing. It is not clear that this kind of support is available in all health facilities or locations, which may leave people in a very difficult situation and their lives at risk from their incontinence.

HELPPAGE AND PARTNERS UNDERTOOK AN ASSESSMENT OF 1,335 OLDER PEOPLE IN COX'S BAZAR CAMPS (2018).³¹

In this study 17% openly admitted that they have incontinence problem and 77% of them stated that they are struggling and not getting any support.

43% of older people with disabilities who have difficulty getting out of living place, also reported to have incontinence.



Incontinence problem



Struggling and not getting any support.



Older people with disabilities reported to have incontinence

3.3.2 Impacts for people living with incontinence without support

DIGNITY

Our focus on dignity is sometimes overlooked, when we are focusing on reaching numbers of people supported, to meet targets. And when we do think of dignity, what do we assume it means? One respondent shared that, **“When we look at dignity, we don’t think about incontinence”**.

But another interview respondent, explained clearly why living with incontinence is fundamentally a dignity issue. They explained that we need to get across to all actors, that if you have it yourself, people don’t want to be around you and that **“there is nothing as undignified”** as leaking urine or faeces. And that it is our responsibility to support people affected by humanitarian crises, with managing their incontinence, **“if we want to restore dignity of**

people we assist”. Another respondent also shared that, **“People’s continence is the root to dignity – non-one wants to take a shit in public, although historically we used to shit in a bucket”**, and also that it can also be difficult and embarrassing to have someone help with continence care. Without being able to privately and easily manage our faeces and urine, it will not be possible to live with dignity.

“We need to share on any innovations – about what women and people can use to help preserve their dignity – to reduce smell and leakage. Smell related to incontinence is more than for menstrual hygiene and people can see it and it has more health and psychological impacts”.

HEALTH

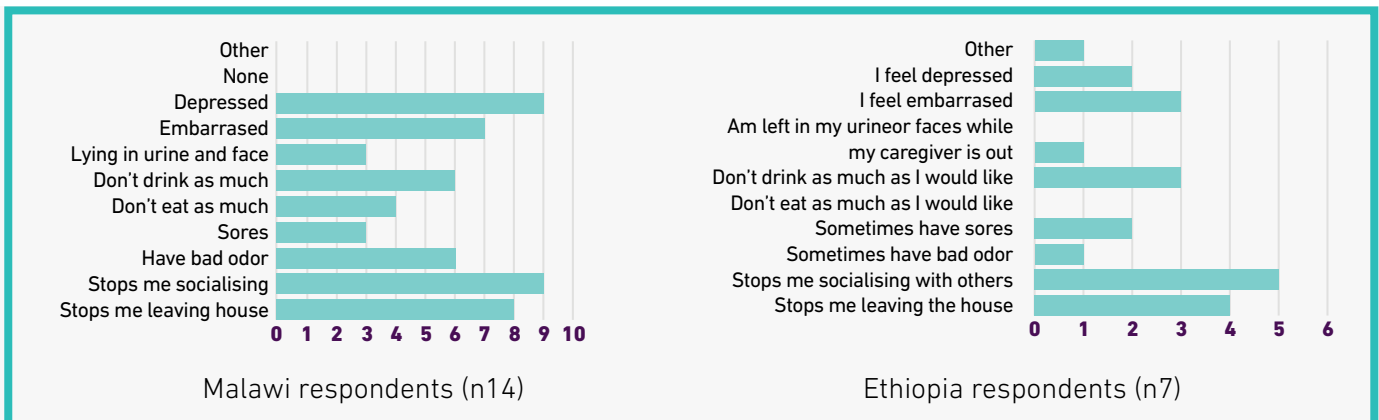
Incontinence is also a health issue. It can occur because of a range of chronic health issues as highlighted above or from traumatic events such as due to delivery of a child, or due to GBV and rape. It can lead to rashes, similar to nappy rash in babies, known as Incontinence Associated Dermatitis (IAD) and for people who are immobile, and hence risk lying or sitting in their own urine or faeces, can also lead to bed sores, also known as pressure sores. The use of catheters can also lead to urinary tract infections (UTIs). Both infections due to rashes and also the pressure sores, can lead to serious health issues and death. So, this condition is much more serious, than many people perceive it is.

Having to handle faeces and urine in the home or shelter, without adequate access to a toilet and water and soap also risks contamination of items within the home or shelter, and hands, and so can

also contribute to the spread of communicable diseases. And in addition, where caregivers need to move or lift the person they are caring for, to be able to care for their toileting or incontinence, this can lead to back problems and other health issues, including mental health challenges for the carer. The following two graphs, indicate the responses of older people living with incontinence in humanitarian contexts in Malawi and Ethiopia, on the impacts for them of living with incontinence³².

The sample size of older people who answered the questions in Malawi and Ethiopia were relatively small – with 41 in Malawi and 39 in Ethiopia. Of the people who responded, 14 in Ethiopia and 7 in Malawi, indicated they had incontinence. The two graphs which follow, indicates the responses from the older people who said they have incontinence.

FIG 8 - IMPACTS FACED LIVING WITH INCONTINENCE BY OLDER PEOPLE



(Credit: OXFAM and partners, 2021)

PROTECTION AND GBV

As well as incidents of GBV which can lead to incontinence and bed wetting starting in children and teenagers, due to the trauma of conflict or other experiences, incontinence can also lead to violence and abuse towards the person living with incontinence.

Examples were shared, where women had explained that they had become divorced because they are not having sex with their husbands, because of incontinence, and that there can be huge issues of domestic abuse and violence within the family because of it.

Multiple examples were shared, where children and teenagers have faced violence and have been beaten and shamed because they are wetting the bed. For example, in Nigeria, children are shamed by having their mattress put outside the house and the child being made to wash it, which brings other children to the area, who not only watch but also chant **“bed wetter”**, over and over laughing. They are also called **“smelling babies”**. Other examples heard about, including some from the people who faced them themselves, include being threatened to be tied to a cheetah to scare them and called **“cheetah man”**, a young teenager who was stood over an open fire to burn her genital area, so that it would sting when she wet herself, and another child who was sat on a termite mound to be bitten, for the same purpose.

Older people and people with disabilities are also at risk of abuse from their incontinence, as their stressed family members, struggle to deal with the basics of just living in a humanitarian context and then have to manage a person’s incontinence on top. Domestic abuse of older people and people with disabilities within the family, is already common and for some people with incontinence, the need for additional body washing and washing clothes and bedding can mean up to five times as much water and soap are needed than for someone without incontinence. If you only have one or two water containers and each time you collect water you have to travel a distance and have to queue up each time, this will add a significant amount of workload and stress for the caregiver.

IMPACT ON CAREGIVERS

Pressures on caregivers include additional burden of buying NFIs, little time for other income generating activities, lack of social life, lack of sleep, not enough time to provide care, not being able to go far from home. Young child caregivers are missing school and all carers face impact on their mental health.

‘I’m a young man, I want to work, but I can’t. It hurts me because I can’t support her, but at the same time, I’m not supposed to be there, I’m supposed to be earning’

Male caregiver

‘Unless you have God in your heart, it is very hard to manage, because sometimes she is doing things unconsciously. You can’t be upset or leave’

Female caregiver

(Documented by OXFAM/HelpAge, 2020)

DEPRESSION AND GUILT ABOUT CAREGIVERS

Depression was another mental health problem that was seen to be experienced by participants living with incontinence. The participants experience of depression, was also attributed to their feelings about loss of independence and being a burden to others. As this participant affirms:

‘I just feel sorry for my son who is always there to take care of a mother, I feel like am being a burden on his life’.

(Documented by St John of God Hospitaller Services, Malawi, 2020)

addition, people with incontinence may be denied food or drink, either by family members, or sometimes the person themselves, will reduce the amount they eat or drink, to reduce the number of times and volumes of urine or faeces they leak. This can lead to dehydration and constipation, which also can have wider health implications.

MENTAL HEALTH IMPACTS

The challenges to loss of dignity, increased stress of managing this condition, domestic and other abuse and violence towards people living with incontinence and as a result of the stigma around it, have significant mental health implications. It is a vicious cycle, in which stress and anxiety around a person's incontinence, can lead to a worsening of the symptoms and less ability to cope with it. A number of examples were shared, of how living with incontinence can lead to suicide. This provides a clear example of how significant the mental health challenges are for people living with incontinence. People really suffer living with this condition. It is difficult, if impossible, to identify any positives from having this condition.

Even in health facilities, mental health is often not prioritized, against the clinical management of more straight forward and easier to see health conditions, which can be measured or seen in blood tests. One respondent shared that **“for example, if there is a malaria peak, then we would not encourage parents to bring children who are bed wetting into the facility”**. This means that many people with incontinence and their caregivers, may be left on their own to deal with the impacts of this traumatic and undignified condition.

SUICIDAL THOUGHTS FROM LIVING WITH FISTULA

“A woman would come begging for help at a health facility every month, in relation to her fistula and then one day she just stopped coming. When asking where she had gone, we were told she has died. It makes you realize that deaths may not be immediate, but they are still happening”.

(Shared by a humanitarian health sector worker)

Older people in Gambella, Ethiopia, also shared that living with incontinence can make them feel suicidal *‘I’m wishing for death, but it is not coming. I punish myself by not eating to bring death quicker’*

Older female household visit participant

‘If no one is taking care of older people, they simply go by themselves to the bush at night to die’

Older female FGD participant

(Quotes documented by OXFAM/HelpAge, 2020)

“It is by God’s grace I am here; else I would have poisoned myself by now. Because the thing worries me. If a man comes to me, they leave me”

Woman who has undergone fistula surgery, Ghana (Quote documented by Research and Grant Institute of Ghana/2021)

“If the family is hiding someone in the home, they may be almost dying and facing trauma, so there is a need for follow-ups”

(Disability sector actor)

LIMITS TO ENGAGEMENT OUTSIDE OF THE HOME (EDUCATION, LIVELIHOOD AND COMMUNITY PARTICIPATION)

Not being able to manage leakage, can severely limit the ability of the person and their caregiver, to be able to engage outside of the home. Queuing for a toilet, or bathing facility, or to collect water or NFIs, may not be possible for some people living with incontinence. Also, they may stay away from engaging with neighbors and in any community activities, or from going in school, leaving them isolated. Likewise, in contexts where people affected by humanitarian crises are able to work, living with incontinence can also limit the person's ability to earn a livelihood. Plus, if they require a carer to support them with their toileting or continence care, the carer is also likely to be limited from undertaking work outside of the home.

'We have the heart to work, but when you think of your situation, you think about how people would react. I'd rather sit at home than be humiliated'

*Male FGD Participant, Malawi
(Quote documented by OXFAM/HelpAge and partners)*

WITHDRAWAL FROM SCHOOL

For children who provide care to the persons living with incontinence, this has resulted in some withdrawing from school. For instance, in a situation in Blantyre, Malawi, the grandmother living with incontinence calls her granddaughter 'her mother'. This puts this young girl in a situation of great responsibility. She stated that since there was no one else to support her grandmother, she had to give up on her education to be available for her.

NOT ABLE TO PARTICIPATE IN CHURCH

Forms of support, especially from religious groups like churches, greatly mediated against isolation and loneliness. However, due to the chronic nature of incontinence, in some cases religious leaders stopping visiting, which caused a great deal sadness. This was affirmed by one participant. He lamented, that he feels forgotten and abandoned by the church he loved. He recalled his dedication in the church choir and emotionally indicated that he felt everyone is no longer caring about him.

Documented by St John of God Hospitaller Services, Malawi, 2020)

SECTION 4

FINDINGS – NCA ENGAGEMENT



4.1

NCA global actions to-date

4.1.1

NCA areas of humanitarian engagement

As an organization, NCA works through a holistic approach as a development, humanitarian and advocacy actor. NCA work towards its two long-term goals of saving lives and seeking justice through three global programmes; WASH, GBV and peacebuilding. The two other global programmatic areas of intervention are WASH, being the most long-standing thematic area, followed by GBV, both for prevention and response. In the last two years, they have also been working on ASRH in humanitarian contexts, with the ASRH programming integrated into GBV programming and not as a stand-alone programme.

FOCUS OF WASH RESPONSES

NCA and its partners work to reduce and mitigate against public health risks for people affected by crises. WASH responses aim to ensure that women, men, girls and boys affected by crisis, have access to safe and reliable drinking water, gender-sensitive sanitation facilities, washing facilities and a clean environment. This is to support people to practice good hygiene, through access to basic hygiene items and information (including menstrual hygiene), which is appropriate and relevant to their immediate needs and in line with the Sphere standards.

FOCUS OF GBV RESPONSES³³

Humanitarian GBV interventions focus on shifting harmful practices and concentrate on preventing practices, that are exaggerated during conflicts, displacement situations and disasters. These include early child marriages, forced marriages and intimate partner violence, in addition to

exploitation, abuse and trafficking in women and girls, for forced prostitution. NCA's GBV in emergencies programmes, focus on establishing a multi-sectoral response to ensure lifesaving and specialized GBV services, either through local partners and/or directly. This includes working on the clinical management of rape and in advising adolescents on health issues. Protection and empowerment of adolescent girls and women, is an important focus for NCA during emergency response and the programmes and where economic empowerment is seen as an important approach in preventing and ending violence against women and girls.

FOCUS OF ASRH RESPONSES³⁴

NCA are currently building capacities in ASRH, focusing on how to integrate it through clear actions. They use GBV as an entry point and they are implementing this work through engaging with women in safe places, providing life skills training and through community outreach. NCA support SRHR services, with particular attention on adolescent girls, to ensure their access to SRHR and particularly information and services. They also engage with partners running health facilities and are also involved in some modern family planning, as well as some work on SRH in emergencies. At the moment, the NCA programming is being funded under the Norwegian Government, NMFA SPA in 5 countries: DCA – Bangladesh; Sahel – Mali and Burkina Faso; Sudan; Nigeria; and DRC. But countries can also raise funds to implement themselves.

4.1.2

Initiating discussion and action on incontinence

NCA started undertaking its first support on incontinence in humanitarian contexts, in 2012 in Liberia. Here they did not include an upper-age limit for receipt of sanitary pads for women and girls, and hence older people also received them for incontinence. This work also continued in Lebanon in 2014, by the NCA partner IOCC in the Bekaa camps. They used the same approach of having no upper age for the provision of sanitary pads. In 2015, NCA recruited a WASH Advisor, with a Hygiene Promotion profile and experience from public health. Her experience of working in care homes with older people living with incontinence in Norway, and passion for incontinence combined with the previous NCA interventions, further ignited NCA's global engagement and future work on incontinence in the organisation. Hence, the incontinence work was built upon, in the Iraq

humanitarian response in Mosul in 2015, and in the response in Tanzania in 2016, for refugees from Burundi. Following feedback from the beneficiaries, the approach also changed from distributing sanitary pads, to distributing incontinence pads (diapers) and extra soap. It was hoped, that this would contribute to help older people manage their incontinence. But at this stage, this work was not undertaken in a systematic way and no formal trial was undertaken, to check the suitability of the response. But they were listening to the needs of people living with incontinence, to better understand their needs. In the NCA Head Office (HO), there was a positive reaction to becoming involved in this area and it started to be integrated into trainings and other activities.

4.1.3

Challenges faced

UNDERSTANDING AND PRIORITISING INCONTINENCE

There have also been some challenges in trying to get this issue prioritized in NCA. For example, initially it was mainly seen as an issue after child-birth and as an issue surrounded with taboos. It was also not seen as a priority in the WASH area, possibly partly down to the demographics of the sector, with most actors in the sector being male and not having personal experience of living with this condition. This is in addition, to most actors, male and female, being relatively more privileged, than the people we support, and having easy access to water and sanitation in their own lives. Therefore, awareness of how difficult it is to live with this condition in a humanitarian context, was limited. It was also not taken as seriously as it needed to be, as it was not seen as a life-saving intervention, and also older people are often a forgotten and invisible group in humanitarian contexts. What gets done, often depends on the awareness and commitment to this issue, of the person who is leading the humanitarian response.

ENGAGING ACROSS SECTORS

NCA respondents felt that NCA is quite open to innovation and trying out new ideas, but the opportunities to link across sectors are not always established. But in general, it was felt that integration across sectors within the humanitarian team, would not be so difficult to do, even though there are different levels and different approaches. It would just require some reaching out to establish linkages and ways of working. The relatively new, ASRH programmes, have also not yet engaged on incontinence, so there would need to be a process to consider the entry points for this engagement and how incontinence services could be provided.

NEEDING LEARNING AND CAPACITY AND CONFIDENCE BUILDING

There is also limited knowledge in the NCA teams and partners and capacity to implement on this issue. So, there is a need to build capacity and confidence to work on this issue. Although some work has already been undertaken, currently only a few people feel confident on this subject. It was also highlighted that in some country programmes, NCA has agreed to work in institutions, but that so far, then have not yet asked about the needs related to incontinence, so the teams will need training on how to do this.

4.1.4 Progress

However, even with these challenges, the following indicates progress made by the NCA:

☑ **STRENGTHENING CROSS-SECTORAL ENGAGEMENT AND LEARNING FROM OTHER WORK**

Over recent years, NCA has been making more effort to engage across sectors, under the flagship of menstrual hygiene management (MHM). They have increasingly been engaging in MHM and have also started increasing engagement in working with and supporting people with disabilities in their programmes. These all offer opportunities, linkages and lessons for the strengthening of incontinence in humanitarian responses.

LIMITED BUDGETS, STAFF DEDICATED TO THIS ISSUE AND CHALLENGES FOR PRIORITISING TIME

Although incontinence is already in the Sphere standards, and included in the NMFA SPA, budgets allocated for it have so far been limited. There is also limited staff time dedicated to this issue and it has not generally been prioritized. Some respondents, also highlighted challenges from repeated deadlines to be met on their wider work, which pose challenges for staff to make time to learn about a newer issue, such as incontinence and to learn how to practically respond to it.

“It makes us nervous to start working on this, as we don’t feel ready without the knowledge, as we do not want to make mistakes”

(NCA staff member)

☑ **NCA WASH INCONTINENCE ACTIVITIES INSPIRED ACTION ACROSS HUMANITARIAN AGENCIES AT GLOBAL LEVEL**

The initial efforts by the NCA to provide support to older people in Liberia, Tanzania, Syria, Lebanon and Iraq, for managing their incontinence, inspired a cross-agency and cross-sectoral discussion on incontinence, at an international MHM workshop in the USA in 2016. This then led to the collaborative publication across agencies, of a paper called *“Incompetent at Incontinence”* in 2017³⁵. It also led to the establishment of the informal global email group on incontinence in humanitarian and LMICs and a few years later, to the strengthening of the WASH Chapter of the Sphere Standards, 2018, on incontinence. See **Sections 5.1.1** and **5.1.3**.

☉ NCA SUPPORTING RESEARCH AND PRESENTING ON EXPERIENCES

NCA and their partners, Rural Development Foundation, in Pakistan, supported an MSc student, Zara Ansari, from the London School of Hygiene and Tropical Medicine (LSHTM), to undertake her thesis. This focused on the experiences of people with disabilities and their carers living with incontinence. Zara presented this research at the WEDC international conference in 2017. NCA also presented on, on their work in humanitarian responses in Liberia in Bahn camp (2012); Lebanon through partner IOCC, in Bar Elias and Bebnine camps in Bekaa (2014); in the Burundi conflict response in Tanzania (2016); and in the Mosul response in Iraq (2016/17).

☉ INTEGRATING INCONTINENCE INTO WIDER TRAININGS

In 2018, incontinence was included in a training run for country offices and roster members. Within these trainings, efforts were also made to try and demystify this condition, including by showing an advert developed by TENA, a supplier for adult incontinence pads. In this advert a man was wearing pads and it tried to emphasize that incontinence can be experienced by anyone.

☉ ONLINE TRAININGS – MHM AND INCONTINENCE

More recently, a training was prepared, called: ***'Supporting personal hygiene: A wash course going beyond hand washing and toilets'***. It focused on what support should be provided to men and women, girls and boys who are experiencing challenges with: menstruation, incontinence and the management of other

bodily fluids. It also covered, washing, bathing, supplies and disposal options. This was then developed further, to become a training, on MHM and incontinence, which has also been made available to other actors, outside of NCA. This can be accessed on: <https://fabo.org/nca/NCAWebinarSeriesMHM>

☉ ENGAGING WITH THE MEDIA

The communications team also started engaging with the media on incontinence. See box.

☉ INDICATOR ON INCONTINENCE

In the 4-year strategic partnership agreement with the NMFA, NCA introduced an indicator for incontinence under the WASH outcome, in their Strategic Partnership Agreement.

INTRODUCING INCONTINENCE IN THE MEDIA WITH ADVOCACY ON MHM IN NORWAY

MHM gained national media attention in Norway, with NCA being a lead agency in gaining this attention. They also linked up MHM and incontinence and introduced its importance and its challenges in humanitarian settings to the media. Key people in NCA spoke at national conferences, challenged politicians and participated in radio shows, highlighting the importance of MHM and incontinence, as well as producing visibility material and posts for social media. It should be noted that the main focus was still on MHM, but it was very positive that incontinence was also introduced.



Åshild Skare, presenting on the work of NCA on incontinence in humanitarian responses, at the WEDC Conference, 2017

(Credit: Impress/Leeds University/2017)

☑ **STRENGTHENING INCONTINENCE IN SPHERE, 2018**

Jenny Lamb (OXFAM) and Kit Dyer (NCA), coordinated the update of the WASH Chapter of ***Sphere Handbook, Humanitarian Charter and Minimum Standards for Humanitarian Response, 2018***. The coordinators, invited members of the informal email group on incontinence, to contribute to strengthening the content and requirements for supporting people with incontinence in the Hygiene Promotion standard. This version of Sphere, therefore had a more comprehensive requirement for the sector to work on incontinence, than in previous versions. See **Section 5.1.3**.

☑ **ENCOURAGEMENT AND SUPPORT TO COUNTRY PROGRAMMES**

Country programmes have been encouraged to work in this area, through engagement of the WASH Technical Advisors.

☑ **INNOVATION FUNDING OPPORTUNITIES**

Under the NMFA SPA, there is an annual grant under the WASH global project. This is earmarked for ***“innovative, sustainable and environmentally-friendly WASH responses”***, and is focusing on the topics e.g.: MHM, incontinence, green WASH, revalorization of waste, or Cash and Voucher Assistance (CVA). It has been launched as a call for interest each year, with these topics mentioned, but so far, no-one has shown interest for any pilots on incontinence.

☑ **MAPPING OF PROGRESS ON INCONTINENCE IN HUMANITARIAN CONTEXTS**

This mapping process was initiated, to document the progress on providing support for people living with incontinence in humanitarian contexts.

☑ **IMPACTS OF THE MAPPING PROCESS**

The process of trying to identify and document, who is doing what in relation to incontinence in humanitarian responses, has already led to a range of people expressing interest in, and joining, the informal global email group. So far, 13 new members have joined the group, directly as a result of the opportunity to be interviewed on behalf of the NCA, for this mapping process. They have backgrounds in WASH Cluster coordination, fistula, SRH, WASH, shelter, disability, occupational therapy, protection, funding, logistics, and camp management. Others are in process.

“This [the mapping process] is a good initiative from NCA - not many people talk about these issues – we need to advocate on this – otherwise coordination will be very difficult”

(NCA country programme actor)

4.2 NCA humanitarian action

4.2.1 Overview of NCA humanitarian action on incontinence

This section, provides an overview of the NCA engagement in incontinence in humanitarian responses undertaken in different countries. Some examples in this table, are also covered in more detailed case studies in **Supporting document 1**.

The dates in the table, indicate the approximate period during which the incontinence-related actions were undertaken. Where exact dates were not known, 2022 has been entered.

OVERVIEW OF NCA HUMANITARIAN RESPONSES ON INCONTINENCE

 COUNTRY: LIBERIA (2012) • TANZANIA (2016)

 DETAILS:

NCA provided support for incontinence in Liberia in Bahn camp in 2012 and in the Burundi conflict refugee response, in Tanzania in 2016. In Tanzania, incontinence was also included in the household survey, and was assumed to sometimes to have been caused by trauma, which led to the displacement of the populations.



NCA and partners undertaking awareness-raising on MHM in Liberia, 2014

(Credit: NCA/2012)

In Liberia, NCA distributed underwear, a bucket, soap and sanitary pads for menstrual hygiene. There was a choice of disposable pads, or washable/reusable cloths, supported by hygiene promotion for all women. The kits were given to individuals, not to families. They did not have an upper cut-off for age, so older women, also received the materials, which they used for their incontinence. Older people expressed satisfaction at the support they received to support their incontinence.



Benedicte Næss Hafskjold and colleagues from NCA, undertaking a household assessment, including some discussions on MHM when appropriate, in Tanzania, 2016

(Credit: NCA/2016)

 COUNTRY: SYRIA AND LEBANON 2014 – 2022

CASE STUDY: CS-NCA-A

 DETAILS:

HYGIENE DIGNITY KITS FOR OLDER PEOPLE WITH INCONTINENCE

NCA worked through local partners in both countries, across almost all governates in Syria as well as in Lebanon, mainly through the local partner IOCC, in the North (Akkar) and Bekaa informal settlements, hosting Syrian refugees. In addition to reconstruction of WASH facilities in Syria and other WASH activities, including NFI distributions, additional incontinence-related items, were also provided prior to 2021. These were provided in dignity kits for older people (soap, incontinence pads (diapers) and other items). They were provided based on assessment of needs, by the hygiene promoters. A post-distribution monitoring, was also undertaken to receive feedback on the items. Although incontinence was addressed, through the MHM activities in Lebanon, it was also identified that men were also in need of materials, including because of disabilities caused by the conflict.



Colleagues from NCA partner, IOCC, undertaking an assessment on MHM and incontinence in Lebanon

(Credit: NCA/2014)



COUNTRY: IRAQ 2015 – 2019

CASE STUDY: CS-NCA-B



DETAILS:

SUPPORTING OLDER PEOPLE WITH NFIS FOR INCONTINENCE

In Iraq, NCA was operational in its programs and in the early days of the Iraq response, focused on supporting internally displaced persons (IDPs), Yazidis, living in IDP camps, in Dohuk governorate. It was a classical camp WASH response, with a strong hygiene promotion component. Later on in 2017, the response also covered IDPs from Mosul, after the end of the Islamic State in Iraq. Since 2016, NCA also started its GBV programme in Iraq, firstly focusing on survivors of GBV, who had escaped, or been released from captivity of the Islamic State. The WASH-related activities in the NCA Iraq response, were to ensure that IDPs in camps had access to safe water and toilets. The programme also had a solid hygiene promotion component, with community mobilizers undertaking hygiene promotion awareness activities, among the camp population and also providing hygiene materials.

The hygiene items, also included items for incontinence. The distributions were not undertaken in a systematic way, and no formal trial was undertaken, but the team listened to the needs of people living with it, and adapted their support. Initially, older people used sanitary pads, that were given to manage their incontinence. However, after consultation between the older community members and NCA hygiene promoters, special adult incontinence pads (diapers), were made available to older people. These were distributed to specific households, upon community identification, through the HP community focal point.

In Iraq, the issue of incontinence, was talked about openly, as the hygiene promotion programme, was more established and especially, because the HP teams, were part of the camp population, and hence had trust and respect among community members. They therefore saw how the older people in their communities and others suffered and struggled with their incontinence.



COUNTRY: GREECE 2016

CASE STUDY: CS-NCA-C



DETAILS:

WASH RESPONSE TO THE EUROPEAN REFUGEE CRISIS

The NCA programme, supported the refugees moving through the camps in and around, Athens in Greece. The programme focused on ensuring the operation of sanitation systems (desludging) and some construction of sanitation facilities, as well as operation and maintenance of water systems. In addition, it also focused on undertaking hygiene promotion awareness-raising, which was supported by the provision of hygiene material. The hygiene material included diapers for adults, upon needs. Needs assessments were undertaken, including MHM and incontinence.

Multiple challenges were faced with this response, because the sites where refugees were living, were constantly changing. Also, what humanitarian actors were allowed to do, also varied from week to week, and the list of camps to be opened and closed, was also not set and changed from week to week, making it difficult to plan. In addition, the target population, the refugees, were in transit, as they all wanted to leave for another European country, which meant that once you had identified a family in need of incontinence products, then maybe after a week, when you wanted to deliver the items, the family may have left or been

moved by the authorities.

 COUNTRY: ETHIOPIA 2020 – 2021

CASE STUDY: CS-NCA-D

 DETAILS:

LEARNING FROM MHM AND PEOPLE WITH DISABILITIES TO SUPPORT ON INCONTINENCE

The WASH team have been supporting South Sudanese refugees in the Gambella Region of Ethiopia, since 2014. They have been working in Jewi camp since 2015 and in 2019, NCA also started a GBV and child marriage project.

MHM enterprises in the Jewi camp and Gambella Town

After realizing that the distributions of sanitary pads from outside of the area, were not happening consistently, the NCA team started working on setting up enterprises to make re-usable sanitary pads. Today there are 15 female members of small businesses in the camp and 15 members in the host town. The pilot ran for one year, until the end of March 2021. Since then, the progress has been amazing and they have become the biggest supplier in the area, with some UN and other NGO agencies, purchasing their products. The establishment of these local MHM enterprises, has offered opportunities for income-generation and to enable access washable/reusable MHM products.



Washable/reusable MHM dignity kits, being made in a small enterprise in Jewi Camp, Gambella

(Credit: Bekalu Dagne Agize/ NCA/2021)

People with disabilities and learning on incontinence:

The team also undertook a learning process with people with disabilities in the camps, to understand how their WASH needs were being met. The issue of incontinence came up during these discussions, as well as during discussions related to MHM. People with different impairments, lacked WASH support. They are a very marginalized group of people and no-one was considering the challenges they were facing. Some of their needs, also have high costs and poor hygiene, can also lead to complications for them.

“Even where different names [terms] were used, some said our mother / father has such a problem and explained the difficulties they face and requested potties and asked for support of materials, such as soap and other things”.

(Country actor)

IOM/Innovation Norway research into innovative incontinence products

The learning from the MHM enterprise development and the assessments with people with disabilities, has also offered opportunities to develop solutions for incontinence. The International Organization for Migration (IOM) has received funding from Innovation Norway, to come up with an innovative solution to address incontinence in humanitarian settings. The project includes an assessment of the main barriers and opportunities in addressing incontinence in a humanitarian context, in this case Ethiopia. This will be followed by a process of market dialogue, to identify ideas for establishing solutions, while seeking to foster a humanitarian-private sector partnership, to come up with a viable solution to be put to test through a pilot in Ethiopia. The IOM has involved the NCA team, and their experience of supporting the enterprises for MHM, to assist in the assessment phase, to identify the particular innovation-related needs for baby nappies and adult incontinence products. The assessment phase was completed and under write-up, at the time this mapping report was published.

 COUNTRY: SOUTH SUDAN 2021

CASE STUDY: CS-NCA-E

 DETAILS:

PILOT FOR E-VOUCHER CASH SUPPORT, INCLUDING PEOPLE WITH INCONTINENCE IN A CAMP AND HOST TOWN

The NCA WASH team in South Sudan, established a pilot e-Voucher cash transfer scheme, to support 232 vulnerable households in Gambella, Ethiopia, in Gumuruk camp and in Gumuruk Town, with host community households. This pilot added cash for these households, which was added on top of the wider cash distribution for hygiene items.

Identification process and e-Voucher cash transfers:

The team went through a number of steps in the establishment of this pilot scheme, including to develop identification criteria for household vulnerability. Two of the criteria, included people living with incontinence and older people in the household. The criteria were agreed by NCA, the local government, community leaders and the donor. Enumerators were trained to undertake a house-to-house identification and registration process in the camp and town, and then the households were identified.

They were given an additional USD 80, in the first month and an additional USD 21 for the next two months, on top of the general cash distribution for hygiene items. This was the same sum, that was also added for each woman or girl of menstruating girl in the household. The e-Vouchers also included a separate wallet for food for the children in the household, so that the hygiene items would be less likely to subsequently be sold, to pay for food. People with incontinence could buy basic items such as bathing soap, laundry soap, water containers, a bucket, a bowl, a kitenge (cloth for wearing, but which could also be used for incontinence protection), underwear (but it was only possible to buy underwear for women or girls using the voucher cash), or sanitary pads (to be used instead of incontinence pads), or a potty for children.



Monitoring of pilot e-Voucher scheme vendors shops and processes, South Sudan

(Credit: Bereket Seifu / NCA / 2021)

Contracts with the vendors and smart phone monitoring:

The team established memorandum of understandings (MoUs) with 6 vendors and supported them with a smart phone, for use during market opening hours, and then which was picked up at the end of the day. This allowed the monitoring of the sales, which could be seen by the vendors, as well as NCA. The vendors were trained in the contract requirements, as well as how to use the smart phone tracking system. Graphs of the purchases made using the three months of funding, can also be found in the longer case study of this pilot, CS-NCA-E - Supporting document 1.

Benefits and impacts of insecurity:

The process of cash transfer, benefits the local community, because it inputs money into the local market. People have the freedom to choose the type of items according to their needs, which is also positive for dignity. It is also useful where access is an issue for the teams, as this system allows the teams to still give money remotely, so the people who receive it, can still go to the market and buy what they need, even when the teams cannot reach the people directly.

Sadly, due to insecurity due to communal violence and other insecurities, the team has not been able to get back to the camps, since the pilot scheme, to either do post-distribution monitoring, or to extend the scheme and integrate it into the general distributions.

 COUNTRY: DRC 2010-2022 (GBV PROGRAMME STARTED IN 2010)

CASE STUDY: CS-NCA-F

 DETAILS:

OPPORTUNITIES FOR STRENGTHENING WASH, GBV, ASRH ENGAGEMENT IN INCONTINENCE

Incontinence is known to be a consequence of sexual violence and for young adolescents giving birth, in North Kivu, DRC. There are people who need to be referred to the fistula hospital, but they don't come

forward, and are hidden living with this condition. Primary health centres, refer women and girls with fistula to the big hospitals, such as the Panzi Hospital (in Bukavu) and the hospital in Goma (HEAL Africa). The hospitals also have psychologists and case workers working in them. Fistula has been seen to be a very sensitive issue and is a big problem, particularly for the social life of the person affected by it.

The WASH response:

The WASH response, works on water access, supporting networks and boreholes and emergency latrines. It also supports latrines in schools and health centres and communication for hygiene behaviour change and they also work on MHM in camps and communities. They undertake this work, through hygiene promotion and community consultation, making sure that girls and women feel safe using the WASH facilities and they are also given dignity kits, including disposable and washable/reusable pads and buckets and soap. The NCA WASH response, has indicators for MHM (NMFA 3.4) and for incontinence and NCA in DRC is asking the partners to report against these. Partners did not have experience on this issue, so capacity building, has been needed.

The GBV team works in both humanitarian and longer-term programmes in DRC:

The GBV prevention activities were the first NCA activities in DRC. The GBV response activities include - medical, psychosocial support, case management, provision of legal advice, supporting for survival, and the management of sexual violence. They work in health structures, including a fistula hospital – training the health workers and providing medicine to these structures. They also work with women and girls in safe structures and provide economic support to survivors of GBV.

The ASRH programme started in 2020 and links adolescents to the GBV programme:

The ASRH programme focusses on SRH education and working with youth groups. They work on skills training and work with parents in groups and train nurses about adolescents and their needs.

Work in a fistula hospital:

The NCA GBV and ASRH team, has been working with the Panzi fistula hospital in Bukavu, on the training of health staff, since the beginning of the NCA programme 12 years ago. NCA are the main GBV partner for the fistula work of Dr Mukwega, who set up the fistula programme and the Panzi hospital. The GBV programme does not work on incontinence directly, and does not deal directly with people themselves. The WASH team have been supporting WASH facilities and improving the water network in the hospital. Women with fistula need easy access to latrines more than others and to showers, so NCA works to support access to enough water and clean latrines.

The existing collaboration in supporting the fistula hospital and the complementarity of the work of the three sectors, offers clear opportunities for working together more on incontinence. For example, to include incontinence in the training of the health workers, which is currently focusing on GBV, sharing information with adolescents through the safe spaced and other activities, and reaching people through the WASH community engagement, as well as support from the WASH team for the management of incontinence.



CASE STUDY: CS-NCA-G



DETAILS:

INFORMATION NEEDS OF NON-WASH ACTORS WORKING ON WASH FOR INCONTINENCE

HEKS-EPER (Swiss Church Aid) are partners of NCA working in Ukraine. They are mostly working close to the frontline and also in the recently liberated areas to try and support the people still living there. Not many agencies are working in these locations, due to the level of insecurity. Mainly older people are left behind, as the younger and middle aged-people are more able are able to leave. Some older people can't move and some don't want to leave. The programme works on the provision of multi-purpose cash grants, food and WASH NFIs and they also provide some mental health and psychosocial support (MHPSS).

Identification of incontinence items for NFI kits:

They are also just starting to consider people with disabilities and have so far distributed children's and adult diapers. The programme has a target to help 2,000 people with incontinence, but there have been some challenges identifying people to provide this support to, as some may conceal their incontinence. The seconded NCA WASH Advisor, has helped to team to develop a questionnaire in the Kobo system, which will be used to understand people's needs. They are still considering what might be most useful through this support and consulted a doctor / health specialist for advice. They have considered the Ukraine WASH Cluster NFI kit lists, as a basis to start from and have added a few more items. At the moment, they are considering to include: incontinence pads (diapers), baby cream with zinc, bed pads (mattress protectors), razors and scissors. But the kits are still being developed, so this may change.

People who received the items so far, received them when they were referred for help for food or hygiene kits. They also asked for incontinence pads (diapers) for older people. People who have collected the incontinence-related items, have tended to come and say they need them for their mother or father. The teams have been asking which sizes are needed? The team is looking at solutions to ensure that incontinence kits, especially the size of the incontinence pads (diapers), are adapted to each individual, suffering with incontinence. Initially they were distributing two sizes of diapers (M + XL), but people have also requested small sizes, so there is a plan to add these. Separating diapers, from the kits and making a stock of different sizes, is also a strategy to assist with this process. They also put the items in a back pack, to make them easier to carry.

This positive experience of working to identify needs and appropriate support for incontinence, has also highlighted the need for clear and straight-forward guidance, for people working at programme level, some of whom may not have a WASH background, as well as people who do. A useful lesson for moving forward, is that we should not make assumptions about what people working on the response, will already know, as some may not have a background in WASH, across agencies. This important consideration, and information on what is needed, will need to respond to the differing backgrounds of people who may work on the response.



CASE STUDY: CS-NCA-H



DETAILS:

OPPORTUNITIES FOR ENGAGEMENT IN INCONTINENCE THROUGH ASRH SERVICES

NCA, set up the programme in Bangladesh, to work through their partner Danish Church Aid (DCA) in the Rohingya response in Cox's Bazar. In the earlier days of the programme, the focus was mainly on sanitation desludging and water supply. The focus on hygiene promotion (HP) in the whole response, received less attention, even though there was a HP sub-group.

DCA supports two primary health care centres (PHC) and one women-friendly space and they work on family care, health care and ante-natal and post-natal care. They provide all services, other than supporting deliveries, for which, they refer mothers to health facilities. They also run awareness programmes, mostly related to SRH. These are on: family planning, ante-natal and post-natal care, safe delivery, abortion services, post-abortion care and menstrual regulation. The GBV team, also runs women-friendly spaces in the camps.

Occasional identification of incontinence and fistula, through health interactions:

The NCA NMFA SPA funded programme in Bangladesh, is being phased out at the end of 2022. The programme to-date, has not yet worked pro-actively on urinary incontinence, but the ASRH team have seen some patients with incontinence and fistula. The fistula occurred during normal deliveries, but the women had not complained about the problem. Likewise, the team have also seen women with prolapse and others with incontinence related to pregnancy. But for most women, their problems are only being identified, when they come for other issues. The DCA SRH team have provided some support for fistula, such as referrals of women with fistula to a locally-based fistula hospital. This is the Hope Foundation Hospital, near Cox's Bazar, which is partly supported by UNFPA and UNICEF.

Resistance by TBAs, to admit problems with fistula:

A FGD held in 2018³⁶ with traditional birth attendants (TBAs), who have links to one of the NCA/DCA supported PHCs, highlighted that the TBAs were reluctant to acknowledge that incontinence or fistula happens, related to child-birth. Some had supervised thousands of births and in the Rohingya community, many young women and girls are married between the ages of 13 to 20 years of age. Some women, around 20 years of age, already have had between 2 to 4 children. Therefore, there are expected to be cases of fistula in such young mothers. It was assumed, that their reluctance to acknowledge this problem, may have been because by admitting it, they may have then felt they were admitting that they are not very good at their jobs. This is a barrier, that could need to be overcome, if the NCA and partners, decide to build the capacity of TBAs in any country context.



CASE STUDY: CS-NCA-I



DETAILS:

FGM AND FISTULA AND OPPORTUNITIES FOR GBV AND WASH ENGAGEMENT

The programme works in rural areas and in town centres with IDPs in Somalia. The needs are overwhelming, but resources are limited. The situation for pastoralists varies, depending on when the birkhads (dammed collections of water), or open wells, dry up and where the rock set-up under the ground is challenging. During these circumstances, people become displaced. There are also farming communities, as well as pastoralists nearer the ocean and Bantu speakers. Conflicts tend to be clan based in Somalia, between different pastoral clans. Also, often, even when women are speaking with women, a man from the community will sit in, or hover to listen to what is being said, which poses a barrier to discussion of some subjects. As people are very private, women also tend to not go the latrines in the day, but wait until later at night to relieve themselves. They therefore avoid drinking water, which can also have health implications.

FGM in Somalia and links with incontinence:

Children face FGM from the age of 8 onwards. It is estimated that 98% of women and girls undergo FGM in Somalia, and through this, all are considered as survivors of GBV. Women and girls who give birth, face their stitching being ruptured and then they are stitched up again. As identified through latest analysis globally³⁷, women and girls with the more severe forms of FGM (Type III, infibulation), are more likely to also face fistula during birth. Infibulation is where a woman or girl has all of their genitals cut away and then everything is sewn up, so only a small hole remains for blood and urine.

Current efforts on GBV and FGM by NCA and partners in Somalia -

UNFPA and partners are working to promote zero tolerance in different populations in Somalia and some people are reducing the practice. Some families are now trying to protect their children from FGM, particularly people in the diaspora. Through the GBV programme, NCA is supporting fistula repairs through providing funds and NCA are also working with Save the Children, to establish zero tolerance on FGM to protect children.

The NCA WASH responses:

The emergency WASH responses, focus on water trucking, provision of hygiene kits, latrine construction by the IDPs themselves, establishing water kiosks and pipes in camps and provision of MHM sanitary kits for women. Traditionally for the management of MHM, holes were dug and women and girls sat on the ground on the holes. The WASH Cluster in Somalia, recommends the use of cloth cotton, which can be cut into smaller pieces, although in schools they provide disposable sanitary pads, as there are challenges, due to lack of water for washing the pads. In the HP activities, the team engages with the girls and give them kits. The programme provides new fabric and they can choose to use their old fabrics for menstruation and use the new one for clothes.

There are also opportunities to strengthen links between the GBV and WASH elements of this programme, and provide additional WASH support for incontinence.

 COUNTRY: MALI & BURKINA FASO

CASE STUDY: CS-NCA-I

 DETAILS:

OPPORTUNITIES FROM AN INTEGRATED CROSS-SECTORAL TEAM

This is a cross-border programme, in camps in Mali and Burkina Faso, which work with an integrated cross-sectoral team. This offers positive opportunities to work across sectors. It has provided opportunities to share ideas from different sectoral perspectives and to provide feedback to each other. The GBV programme is central to the programme, and establishes safe spaces in communities. They also work on mental health issues in the camps and have Mental Health and Psychosocial Support (MHPSS) activities. NCA has its own expertise in this area and they also work with in-country experts. WASH complements the work of the GBV and SRH activities and the programme also has a pilot Menstrual Health and Hygiene (MHH) project, now in its second phase.

The NCA WASH Advisors have been working to provide organisational training for the local partners, bringing in different experts. Capacity building was provided for both staff and partners, who were trained together. They have already involved the health specialist on menstruation, and hence were able to have technical inputs and to build on this expertise. They will provide training with an introduction to MHM and incontinence in January 2023. It is considered that the programme, could potentially work on incontinence in safe spaces and could also offer support on mental health through these activities.

 COUNTRY: AFGHANISTAN

CASE STUDY: CS-NCA-I

 DETAILS:

CONSIDERING NEED FOR FEMALE AS WELL AS MALE STAFF FOR WORKING ON INCONTINENCE

NCA WASH programme in Afghanistan, works through partners in 4 provinces and focusses on building capacities in climate resilience, hygiene promotion, sanitation using CLTS, water supply and participation. There are separate WASH teams working on development and humanitarian responses, which respond to climate change, floods and earthquakes. They also work WASH in health centres, clinics and schools as well as at community level.

They have undertaken needs assessments, but nobody specifically asked for support on incontinence at that time. The team feels that if questionnaires are distributed in clinics, they could get a better picture of how many people are living with this condition. There are also other sector partners working in Afghanistan, such as IRC and NRC, who already work on areas such as provision of school toilets with rooms for managing menstrual hygiene. These might also have potential for being used to manage incontinence.

One of the challenges for possibly working on incontinence, is that the team is currently all male, with one coordinator and two officers who are engineers, although there is one female GBV officer, working on social inclusion. It is felt that having a female team member with a health background, would help the team work on HP and CLTS, as well as MHM and incontinence and can also help the programme, support female priorities. When a female staff member is in the team they would travel with a 'Mahram', where they also employ her mother, brother or father, to accompany the female staff member.

4.2.2

Lessons - Challenges to integrating incontinence into programming

The following challenges have been highlighted through the experience of NCA working on incontinence in its humanitarian responses, across country contexts.

LACK OF SYSTEMIZATION OF COMMITMENT TO SUPPORTING PEOPLE WITH INCONTINENCE:

- At the moment, actions on the ground, tend to follow whether the staff team members have a particular interest in this area, rather than being systematic in all programme areas

VARIABILITY AND VULNERABILITY OF PEOPLE AND THEIR SITUATION, POSES CHALLENGES:

- Communal fighting and insecurity, can impact on access to undertake post-distribution monitoring, and limits opportunities to learn about good practices and rolling-out support
- It is difficult to plan for software and support for incontinence, when the response is not well planned, what humanitarian actors are allowed to do and camp locations keep changing
- When people are in transit, assessing and planning for incontinence support, becomes more challenging
- Reduction in aid, means that households tend to prioritize finding funds for food and other basic needs, so they may be selling hygiene items

HIGH COSTS OF DISTRIBUTION OF INCONTINENCE PADS:

- Blanket distributions would be easier and would reduce the sensitivity-related challenges around identifying specific people living with incontinence – but this would also be expensive for the supply of incontinence pads
- Increased prices due to hyperinflation, poses challenges for the continued provision of NFIs

HOW TO IDENTIFY PEOPLE CAN BE CHALLENGING:

- Identification of people with incontinence can be challenging, due to taboos and people being hidden by families
- In IDP contexts, people don't know what the term incontinence means. It is also culturally sensitive, so people may not openly talk about it, even though many people have it
- People with disabilities struggle to get access to water and are often hidden in their houses, so this can pose challenges to identify where they are and incontinence challenges they may face
- TBAs may be reluctant to acknowledge that incontinence or fistula happens related to child-birth, which may occur, because they feel it would imply that they are not good at their job

DIFFICULTIES WITH ESTABLISHING SUSTAINABLE SUPPORT:

- The e-Voucher system, whilst positive in a number of ways, is not a long-term solution, when external funds are supporting it (in the same way as any form of externally-funded aid)

GAPS IN STAFFING, GUIDANCE, KNOWLEDGE AND CONFIDENCE OF STAFF AND PARTNERS:

- Where there is also a male staffing culture, which can make difficult to talk with women; more female staff are needed to facilitate these conversations

- There is also a gap in the knowledge on incontinence of WASH, health workers and other
- When the programme is working remotely, it is harder to supervise new activities
- It is also a new topic in humanitarian work, and there is not much information in terms of guidance or standards
- Some staff and partners working on incontinence, may be generalists and not have WASH, GBV, Health or SRH experience, and hence, guidance needs to also be suitable for their learning needs

4.2.3

Lessons - Opportunities for strengthening incontinence engagement in the future

The following opportunities have been identified, through the experience of the NCA working on incontinence in its humanitarian responses, across country contexts.

NCA already works across three key sectors, which are very relevant to incontinence:

COLLABORATION:

- In a number of countries, there are already WASH, GBV and ASRH programmes, which offers opportunities to collaborate on incontinence
- In some countries, efforts have already been made to see where it could be possible to integrate and coordinate across sectors – WASH, GBV and ASRH
- All three teams have good opportunities to discuss this subject with different groups in the community and to also help their partners get in touch with people who have incontinence, to encourage them to get support
- Incontinence may also offer opportunities to engage with other groups of people, such as people with HIV

WASH:

- When people are identified with incontinence through GBV/ASRH activities, this can also offer opportunities, to provide WASH support
- WASH could include incontinence, in hygiene promotion and MHM activities
- Existing MHM learning, also offers learning relevant to incontinence
- When the programme goes to work hygiene promotion in communities and to offer support, this is also an opportunity to engage with people in their own homes
- In addition to products, sanitation, bathing and laundry infrastructure and facilities, are also needed near to shelter, to be able to manage incontinence effectively
- Links might be possible through schools
- Awareness can be increased on the existence of and needs of people with disabilities, by making water, sanitation and hygiene infrastructure and services accessible (including access to water supply, toilets, showers, laundry spaces and waste management).

GBV AND ASRH:

- The NCA GBV team, already works to support women, girls and children, through safe spaces and to prevent child rape. These efforts, could be an entry point to also talk about incontinence
- For adolescent girls, discussions on early marriage and child marriage, have already been linked with WASH and MHM, so this kind of linkage could also be considered for incontinence.
- Incontinence is one of the complications of rape and sexual violence and the GBV team already provide training on the clinical management of rape. So, it would not be difficult to incorporate new modules on this subject, into the existing health worker trainings
- The same guiding principles will also apply for GBV and health workers, over confidentiality and the sensitivity of these subjects, which can then easily be adapted
- Where NCA works through PHC, SRH/ASRH and GBV services, with professional staff, such as doctors, nurses, midwives and other staff, this also offers opportunities for entry points, to meet people living with this condition, and to share information and provide support
- The programme should work with traditional birth attendants (TBAs), who are often untrained, to know what to do about leakage and how to support woman and girls
- The PHCs are also networked with community workers and TBAs, so they could also offer an opportunity to raise awareness on this issue, and the need to refer women and girls giving birth to health facilities, to reduce the risk of obstructed or protracted labour
- People need information and knowledge on the subject of incontinence and to understand its links to FGM

THERE IS A NEED TO SYSTEMATIZE INCONTINENCE INTO WASH AND OTHER SECTORAL ASSESSMENT TOOLS:

- Integrating incontinence as a standard section of WASH assessment and monitoring tools, including rapid assessment tools, would help to systematize the process, and build understanding, capacities and confidence on this issue

GUIDANCE AND CAPACITY BUILDING WILL BE NEEDED FOR STAFF AND PARTNERS:

- Training would be needed for the NCA teams and partners, to integrate this into NCAs work
- There is a need to develop guidance materials, tools and training materials, which can be understood and used by more generalist, non-WASH team members, supporting NFI distribution for people living with incontinence, as well as more experienced WASH staff
- There is a need and opportunities for advocacy of the local health sector, government bodies, and implementing NGOs/INGOs, to incorporate incontinence in currently used IEC materials, and awareness messages and modules, for refugees and host communities

LEARNING HOW TO DISCUSS INCONTINENCE SENSITIVELY, CAN ENCOURAGE PEOPLE TO SPEAK ABOUT THEIR INCONTINENCE:

- People are willing to speak about incontinence, when the opportunity is opened up for them to do so and the questions are asked sensitively

DISTRIBUTIONS, COMMUNICATION WITH PEOPLE WITH THIS CONDITION AND CAREGIVERS AND POST-DISTRIBUTION MONITORING:

- Communicating with people living with incontinence and their caregivers, about their needs, is very important
- e-Voucher cash transfer schemes, can be used to support people with incontinence, if the identification process is established well
- Post-distribution monitoring, including through FGDs, is very important to check if the support is appropriate to people's needs, or improvements can be made
- Although they can be useful, sanitary pads are not the most suitable for many people living with incontinence, particularly people with more severe forms of incontinence
- There is a need to consider different sizes and absorbency of products
- There is a need to work out systems, to distribute different sized incontinence pads at scale

4.3

NCA – Current knowledge and experience on incontinence

An online survey was run for NCA staff and partners, across WASH, GBV and ASRH sectors and was also open for colleagues with other sectoral or supporting responsibilities, if interested. Some questions were compulsory and others were optional, so that participants could choose to respond anonymously if they preferred. After the introductory webinar was completed, the participants were given one week to complete the survey. The participant numbers, backgrounds and locations can be seen in **Section 2.4**.

PURPOSE OF THE ONLINE SURVEY

1. The purpose of this online survey, was to help the NCA understand the level of knowledge, confidence and interest of NCA staff and partners, in the area of engaging with and supporting people living with incontinence in humanitarian contexts.
2. It aimed to understand, actions taken so far, as well as the barriers and challenges and ideas for how it can strengthen the work of the NCA in this regard.

ONLINE SURVEY RESPONSES

In summary, the findings were:

1. When asking the participants to rate your current knowledge on incontinence, there was a reasonably wide range of responses, with half being on the 'less confident' and half on the 'more confident' in their knowledge on this issue. Considering some of NCA teams have been working on this issue and other teams have not worked on it yet, this range of responses makes sense.

2. In terms of actions undertaken so far, more people have been involved in discussions on the subject in WASH meetings, or in trainings. Some have discussed across sectors, but only occasionally. Only a few, shared they had undertaken actions related to incontinence, such as providing NFIs, or improving WASH facilities for a person affected by this condition.
3. In relation to having spoken with someone with incontinence, out of 18 respondents: 12 people responded 'never', 3 said 'only once', and 3 people said 'occasionally'. This is an important finding, as an important step in the process of learning about this subject, is to hear from people living with incontinence themselves, the challenges they face and their needs for support. Hence, facilitating opportunities for staff and partners to learn from people themselves, would be a useful step in building understanding and confidence, as part of capacity building.
4. The key barriers to engage with people living with incontinence in humanitarian responses, revolved around a lack of knowledge, a lack of funds, and not knowing how to talk about the subject, or how to practically respond. The next group of barriers, included not believing it is an important or priority issue, and feeling it is not life-saving. The next group, were around feeling embarrassed to talk about the subject and not wanting to offend. The last group, and hence the issues which were ranked as being the less important barriers, were around it being too difficult, not having enough time and it not being our responsibility.

5. It is expected that it will be possible to respond to barriers, through the development of guidelines, tools and capacity building, as well as increasing commitment of senior management and donors, in order to increase funding availability.
6. In terms of support or actions, to strengthen engagement with and support more people living with incontinence, the responses were overall, quite evenly spread when considering the weighted average responses; people gave a range of different combinations of answers.
7. Opportunities to share experiences with other programmes, to see case studies showing how this issue had been practically responded to and guidelines, checklists and capacity building were the highest ranked priorities, for support actions. But following not far behind, were increased engagement by senior management and funding opportunities.

For more details and graphs of the responses, see **Annex II.**

SECTION 5

FINDINGS – GLOBAL HUMANITARIAN ACTORS' ENGAGEMENT

Shirley's commode chair
(Credit: Vanuatu, Allison Coleman
/ World Vision Vanuatu / 2021)



5.1 GHA – Supporting actions to-date

5.1.1

Global email group on incontinence

HISTORY AND FORMATION

Incontinence has been a very overlooked subject in humanitarian response and also in the global development sector. It was difficult to identify even brief mentions of this condition, in many humanitarian-related reports, guidance and standards. Actions related to fistula and the support provided by fistula hospitals, was the main information touched upon in documents, in which incontinence was mentioned, until a few years ago.

In 2011, a WaterAid/SHARE team were working on **'Menstrual Hygiene Matters'**,³⁸ which was an effort to collate practical progress on supporting women and girls on menstrual hygiene and pull together good practice, as it was known at the time. During this process, one of the team members, Sue Cavill, suggested that a section should be inserted into the manual on incontinence, because some people use sanitary pads to manage their incontinence. An expert in Obstetrics and Gynecology, was consulted and incontinence was included in a short section (p320, section T7.3.2 **'Incontinence, fistula, post-natal mothers and sanitary protection'**). Menstrual Hygiene Matters, which was published in 2012 and co-published by 18 agencies. Following this recognition, some efforts were then made by the authors, between 2012-16, to try and get other actors to recognize this gap in international development and humanitarian engagement. This was particularly through starting to integrate short discussions on incontinence, into training sessions on MHM, and developing initial guidance on the selection of products for MHM and incontinence (for IRC, 2013; UNHCR, 2016³⁹). But the main focus was still on MHM and it was challenging to get actors across agencies, interested enough in this subject, to want to work on this issue on the ground.

SHARE via WaterAid, managed to get a small amount of funding and Chelsea Giles-Hansen, prepared a briefing note (2015), on **'Hygiene needs of incontinence sufferers; How can water, sanitation and hygiene actors better address the needs of vulnerable people suffering from urine and / or fecal incontinence in low- and middle-income countries'**.⁴⁰

The opportunity to get this subject talked about on in a wider group, came in 2016, during a meeting, held in New York, as part of the consultation on the development of the Emergency MHM Toolkit, being developed by Columbia University and the International Rescue Committee (IRC). By chance, during a participatory exercise, Benedicte Hafskjold of NCA, and Sarah House, ended up in a sub-group together, discussing that **NCA had already been distributing sanitary and incontinence pads to older people to help them manage their incontinence - in Liberia, Lebanon/Syria, Iraq and Tanzania/Burundi humanitarian responses**. So, the pair decided to put out a call to other participants, to meet in a break, to talk about incontinence and whether they have seen it in their work and have undertaken any actions on this subject.

A group of participants, came together and had initial discussions on this subject: Benedicte Hafskjold (NCA, WASH); Biserka Pop-Stefanija (MSF, WASH/Health); Chelsea Giles-Hansen (IFRC, WASH); Michelle Farrington (OXFAM, WASH/HP); Minja Peuschel (Save/Global Protection Cluster); Nicole Klaesener-Metzner (IRC, WASH); and Sarah House (Independent, WASH). Between this group, a range of examples were shared, of where they were aware of people living with incontinence in

humanitarian contexts and the challenges they faced. This included children wetting their beds, due to traumatic experiences in conflict situations, and where older people, people with disabilities and other people in health facilities, had been met struggling with incontinence. The group acknowledged it was a problem, and that very little, if anything was being done pro-actively about it on the ground, except for the work that NCA had started. The group decided to stay in touch and to see what opportunities would come up, to start to get this issue talked about and find solutions to encourage action.

Shortly afterwards, the group published a paper on the experiences of the group so far, and a few more members joined the group to work on this paper - Eric Weerts (HI, OT/Disability); Jane Wilbur (WaterAid, WASH/Disability); Sue Cavill

(Independent, WASH); Erin Flynn (WaterAid, research manager); Kate Brogan (IMC, WASH); Keku Ackom (IMC, Health); Ricardo, Pla Cordero (HI, Disability). The paper '**Incompetent at Incontinence - why are we ignoring the needs of incontinence sufferers?**'⁴¹ was published in Waterlines, in 2016, including some personal financial contributions from some of the authors, to ensure the paper would be open access. It was the communication process to develop the paper, which then expanded, to become the start of the informal email group on incontinence.

THE INFORMAL GLOBAL EMAIL GROUP ON INCONTINENCE IN LMICS AND HUMANITARIAN CONTEXTS

The global email group, is an informal group of professionals, working across sectors in humanitarian and low- and middle-income (LMICs) contexts around the world. The aim of this international group, is to be able to share our learning, and learn from each other, on how to better work with and support people with incontinence, living in humanitarian and low- and middle-income contexts around the world. This group is free to join and is being facilitated and run on an informal and voluntary basis.

The group currently has around 100 members, across a wide range of professions: WASH

For anyone interested in joining the group, please contact one of the coordinators – Sarah House, Chris Chatterton, or Preetha Prabhakaran, through: Lmic-incontinence+owners@googlegroups.com

(including hygiene promotion specialists), environmental health, shelter, logistics, disability, older persons, a risk mitigation specialist, child protection, protection, GBV, a fistula surgeon, a urologist, nurses, sexual and reproductive health specialists, midwives, occupational therapists, a medical anthropologist, a sociologist, engineers (working on surgical technologies, innovation, design/mechanical, civil), gender equality and social inclusion / equality and non-discrimination advisors, and a menopause and WASH specialist. There are members who are practitioners, managers and researchers, in a number of the above fields, from UN agencies, FBOs/NGOs, donors, universities and independents, with humanitarian, development and higher-income experience. A few people in the group, work on incontinence full-time, but most only work on this issue part-time, or have joined to learn about the subject.

OUTPUTS OF THE INFORMAL GLOBAL EMAIL GROUP

A wide range of sharing has occurred through the group, since its formation, including sharing learning and research, and requesting information from other members, or feedback on draft research tools, or post-distribution monitoring formats. In addition, during the process for

development of the 2018 version of Sphere⁴², the email group was approached, to help strengthen the content related to incontinence, joining it with the strengthened inputs for menstrual hygiene. A number of group members contributed.

In addition, increasingly, members of the group were also being asked for guidance and information on incontinence and hence were repeatedly sending links and information by email. To simplify this, in 2018, Sarah House started to work on collating the information, links, good practices, case studies and references into four documents, with the aim that these could then be shared with new members, or other people contacting the group asking for information. Clare Scott, a PhD student

at Leeds University, later also kindly came on board, to help complete the documents and a number of other group members also kindly contributed inputs and reviewed the documents. This process resulted in the production of four informal documents – **Guidance, Summary, Case Studies and References, published by the informal email group on incontinence**⁴³.

5.1.2

Sectoral leadership on incontinence

WHICH SECTORS SHOULD LEAD ON INCONTINENCE

Which sectors should lead on incontinence, and which sectors should coordinate to respond to this issue, has been the subject of discussion. This discussion will need to continue, as this is very much a cross-sectoral issue. The following examples, highlight some of the dilemmas, organisations are struggling with internally, on the cross-sectoral question. This has similarities with the discussions that have also been had on MHM.

ORGANISATION 1 - One agency, shared that they have been facing challenges as to where to place the issue of 'assistive technologies' more generally, and how to coordinate for them? Initially this subject tended to be considered as health related, whereas the social protection stakeholders tended to have the engagement with people who will need them during service delivery. But they are not considered much, as having this role, with regards to assisted products. So, to try and solve this issue, the protection team, who also lead on disability and inclusion, have started a collaboration with the health unit. They have also employed a consultant, to look at assisted services and rehabilitation. This also considers where incontinence should sit and how they can share responsibility. WASH has not yet been involved, although they are an entry point to communities for WASH activities and for the provision of WASH facilities, which is where the needs are identified, so they should also be involved.

“There are continued discussions on whether incontinence should be under protection, gender or inclusion – or if health should take the lead (this organisation does not have a person responsible for SRH). In relation to MHM, protection has some engagement in MHM but they do not take responsibility for all the products, so WASH has ended up taking the lead”.

(Organisation 2 - WASH humanitarian actor)

One respondent shared that their organisation mainly focusses on women of reproductive age and children and that, “older people are invisible to us, so we don't programme for them, and barely do anything for men”. In relation to MHM, “SRH colleagues did not bite”, they only seem to focus on women until they give birth.

(Organisation 3 - WASH humanitarian actor)

EVERYONE'S RESPONSIBILITY – AND HENCE NO-ONE'S RESPONSIBILITY?

A number of humanitarian actors shared their concerns about the risks for who takes responsibility:

“One of the challenges, is that it seems blatantly relevant to protection, health, reproductive health, WASH – so it should be like MHM. It is an obvious thing to do, but it is at risk of being an orphan child – It's everyone else's responsibility and hence it ends up being no-one's responsibility”.

“Incontinence should be managed at the same level as disability – we should not try to work as specific separate items on this” – but another humanitarian actor was also concerned that: “Cross-cutting issues are often left behind, with Disability or Inclusion Focal Points, just added on”

ROLE OF CLUSTER COORDINATORS IN LEADING ON INCONTINENCE

The Cluster Coordinator role in each sector, will be critical to ensuring attention on this issue. The following box, highlights this from the WASH Cluster perspective.

WASH Cluster Coordinator's role in incontinence

One respondent from the WASH Cluster, highlighted why the WASH Cluster Coordinator role is critical, in supporting efforts on this issue. They highlighted that the WASH Cluster Coordinator role, provides oversight and coordination of activities of a group of agencies working in WASH. They check what is being done, in terms of supply of NFIs and water or sanitation provision and the overlaps and gaps. They are in a good position, as they are not implementing, so can step back and see the bigger picture. If they set priorities, such as specific quality standards, people will usually follow this – and if not, they can also see the demographic, which organisations do not and will follow up.

Global WASH Cluster's – Field Support Team

It was also highlighted that the Field Support Team, which exists in the WASH Cluster globally, will be an important team to involve in this issue, as they support humanitarian responses across contexts. There is also a person-centered lead, within the team, who would be an appropriate person, to encourage improvement in this area globally.

INTEGRATION INTO SPHERE AND THE HUMANITARIAN RESPONSE PLAN

The Inter-Agency Steering Committee (IASC) - has the overall decision making, including on cross-sectoral priorities and hence, their understanding and commitment will be needed. This is in addition, to keeping incontinence in a prominent location in Sphere.

It was also proposed that it needs to be integrated into the **Humanitarian Response Plan (HRP)**, as this then hardwires these issues. People will then

know they have to do it and it will be expected, if they want to use the pooled funding. The pooled funding, is divided up at the overall discretion of coordinators and must be used to support the HRP. If incontinence is in the immediate priorities, there would be a good scope for them to be taken up.

5.1.3

Standards and guidance on incontinence in LMICs and humanitarian contexts

SPHERE HUMANITARIAN STANDARDS

SPHERE, 2011

Incontinence had a small mention in the 2011 edition, in the WASH section. See box.

The health section of the 2011, version of Sphere, seems to overlook the issue of incontinence. Even mentions of sexual violence and emergency obstetric and newborn care (pp 327-8), do not mention the risk of fistula, or incontinence, and the need to support the person who lives with it.

SPHERE, 2018

Sphere Association (2018) *Minimum Standards for Humanitarian Response* <https://www.spherestandards.org/handbook-2018/> - Three chapters mention incontinence:

SHELTER CHAPTER, 2018

There are two mentions of incontinence in the Shelter Chapter of Sphere, 2018. Both link to the WASH Chapter NFI section, related to incontinence: p259, Shelter Chapter – under the guidance notes for household items; and p256, Shelter Chapter – under protection.

SPHERE, 2011 (PP95-6, 2011)

Hygiene promotion standard 2: Identification and use of hygiene items

The disaster-affected population has access to and is involved in identifying and promoting the use of hygiene items to ensure personal hygiene, health, dignity and well-being.

GUIDANCE NOTE 7 – *‘Special needs: Some people with specific needs (e.g. incontinence or severe diarrhoea) may require increased quantities of personal hygiene items such as soap. Persons with disabilities or those who are confined to bed may need additional items, such as bed pans. Some items may require adaptation for sanitary use (such as a stool with a hole or commode chair)’*

See the box which follows for the entries in the Health Chapter of Sphere, 2018.

HEALTH CHAPTER OF SPHERE, 2018

The health section of Sphere, has a couple of mentions of incontinence in, related to assistive aids. See p346, Health Chapter – under key actions related to: **“stocking palliative medicines and appropriate medical devices such as incontinence pads and catheters at healthcare facilities”**; and **“Provide supplies for home care needs, such as incontinence pads, urinary catheters and dressing packs”**.

But incontinence is NOT MENTIONED in the following sub-sections – this should be discussed while developing future versions of Sphere:

Emergency obstetric and newborn care (p329)

Sexual violence (p331)

Injury and trauma care (p335) – it only mentions possible need for crutches and wheelchairs

Palliative care (p346)

WASH CHAPTER, 2018

Following a pro-active request from the humanitarian advisors managing the development of the WASH Chapter of the 2018 version of Sphere, Jenny Lamb (OXFAM) and Kit Dyer (NCA), asked members of the informal email group on incontinence, to contribute to strengthen

the content and requirements for supporting people with incontinence. The WASH Chapter - Hygiene Promotion section, Standard 1.3 (p102-104), is the main section on incontinence in Sphere. See the box which follows.

WASH CHAPTER - SPHERE, 2018 (PP102-4A)

Hygiene promotion standard 1.3: Menstrual hygiene management and incontinence

Women and girls of menstruating age and females with incontinence, have access to hygiene products and WASH facilities that support their dignity and well-being.

KEY ACTIONS RELATED TO INCONTINENCE

- | | |
|---|---|
| 1. <i>Understand the practices, social norms and myths concerning menstrual hygiene management and incontinence management, and adapt hygiene supplies and facilities.</i> | 2. <i>Consult women, girls and people with incontinence on the design, siting and management of facilities (toilets, bathing, laundry, disposal and water supply).</i> |
| 3. <i>Provide access to appropriate menstrual hygiene management and incontinence materials, soap (for bathing, laundry and handwashing) and other hygiene items.</i> | 4. <i>For distributions, provide supplies in discrete locations, to ensure dignity and reduce stigma, and demonstrate proper usage for any unfamiliar items.</i> |

KEY INDICATORS RELATED TO INCONTINENCE

- | | |
|--|---|
| 1. <i>Percentage of people with incontinence that use appropriate incontinence materials and facilities</i> | 2. <i>Percentage of recipients satisfied with incontinence management materials and facilities</i> |
|--|---|

Guidance Notes –

Addressing menstrual hygiene management and incontinence in crises: “Successfully managing menstrual hygiene and incontinence, helps people to live with dignity and engage in daily activities. In addition to providing access to hygiene items, it is important to consult with users about disposal mechanisms at home as well as in communal facilities and institutions such as schools. Toilet facilities should be adapted and space provided for laundry and drying facilities”.

The guidance notes then go on to discuss who may live with incontinence, taboos and risks, supplies and facilities, minimum NFI supplies, replenishment of supplies, and considerations for people in different contexts.

OTHER HUMANITARIAN-AND LMIC-RELATED GUIDANCE WHICH MENTION INCONTINENCE

This section highlights a range of guidance, standards and other documents, in which incontinence has been mentioned in the past years. For more details, such as authors, links and additional publications – see **Annex III.2** and **Supporting document 2**.

GUIDANCE DOCUMENTS

These included a publication by OXFAM-GB, on excreta disposal for people with disabilities in emergencies from 2007, **Menstrual Hygiene Matters**, which was published by 18 organisations, led by WaterAid and SHARE, in 2012, and documents prepared on the selection of MHM and incontinence materials, for an IRC training in 2013, and later adapted for UNHCR in 2016. Plan International and the USAID/WASH Plus programme, with the Government of Uganda, published training materials for caregivers, supporting people with HIV in 2014, which includes guidance on supporting people who are bed bound, with their toilet needs. Chelsea Giles-Hansen, undertook a desk study on behalf of WaterAid and SHARE in 2015, which specifically focused on the needs of incontinence sufferers in LMIC and humanitarian contexts; and the first collaborative publication on incontinence, was published in 2016, called **Incompetent at incontinence – why are we ignoring the needs of incontinence sufferers**, by a group of people, who subsequently formed the start of the informal email group on incontinence in humanitarian and LMICs. UNHCR, briefly included incontinence in its MHM section of its **Protection, Accountability and WASH Briefing Note**, in 2017 and World Vision and CBM Australia, prepared practical guidance with clear images and tips on supporting people with incontinence in Sri Lanka, in 2018. Then in 2019, in response to increasing practical questions about how to work on incontinence, the informal email group on incontinence in humanitarian and LMICs, pulled together and published, four documents: **Guidance on supporting people with incontinence in humanitarian and low- and middle-income contexts (LMICs)**, a 4-page Summary of the guidance document, case studies; and references. In 2020, the Sanitation Learning

Hub, published, **Incontinence: We Need to Talk About Leaks, and in 2022 the Red Cross and Red Crescent Movement, published a fact sheet on supporting people with incontinence from the WASH perspective**.

STANDARDS, STRATEGIES AND GOVERNMENT GUIDELINES

In addition to the 2018 version of Sphere, the 2015, IASC version of the **Guidelines for Integrating Gender-Based Violence Interventions in Humanitarian Action**, included two mentions of the provision of hygiene and dignity kits and need for better access to WASH facilities for males and females, who have suffered trauma due to rape and have incontinence. The Age and Disability Consortium prepared, **Humanitarian standards for older people and people with disabilities**, 2018, also mentions incontinence, as does the UNHCR document on **Working with Older Persons in Forced Displacement, 2021**. The Government of Bangladesh and the WASH Sector in Cox's Bazar, both mention incontinence briefly in their operational guidelines, 2017, and in the WASH sector strategy, 2018, respectively.

RECENT UPDATES TO FISTULA GUIDANCE

The WHO, **Recommendation on the length of bladder catheterization following surgical repair of a simple obstetric urinary fistula**, and the UNFPA, **Guiding principles for clinical management and program development - Obstetric Fistula & Other Forms of Female Genital Fistula**, also known as the **"Orange manual"**, were both updated in 2021.

WASH FOR PEOPLE WITH DISABILITIES

There are also a wide range of guidance documents, on design of WASH adaptations for people with disabilities in LMICs. These have been prepared after the publication of the publication by Jones and Reed, in 2005, on **Water and sanitation for disabled people and other vulnerable groups: Designing services to improve accessibility**. Plus, there are a range of websites, with useful information, coordinated by CBM, International Disability Alliance, WaterAid Australia and others.

5.1.4

Research from LMICs and humanitarian contexts

MASTER'S THESES AND PHDS

A number of pieces of research, which have specifically focused on incontinence in LMICs or humanitarian contexts, add to the body of evidence, which can be used to encourage increased engagement in this area. For more details, such as authors, links and publications - see **Annex III.2** and **Supporting document 2**.

COMPLETED MASTER'S AND PHD THESES

These include a master's thesis by Clare Rosato-Scott, from Cranfield University, supported by Plan International, on *Incontinence in Zambia: Understanding the coping strategies of sufferers and carers, 2017*; a master's thesis by Zara Ansari, at LSHTM, supported by NCA and partners, on *Understanding the coping mechanisms employed by people with disabilities and their families to manage incontinence in Pakistan, 2017*. In 2019, Amita Bhakta, from WEDC, Loughborough University, also prepared a PhD thesis, on *Opening the doors to the water, sanitation and hygiene needs of women from the onset of the perimenopause in urban Ghana*, which also included some information on incontinence.

PLANNED AND ON-GOING MASTER'S AND PHD THESES

Clare Rosato-Scott, of Leeds University is currently completing her PhD thesis related to *children with incontinence in humanitarian settings*; and at Tampere University, in Finland, there are three masters' theses under preparation, under the

auspices of the Pad Project. These include theses by: Silja Talvinen – focusing on *incontinence issues inflicted by sexual violence, and how it is voiced out, encountered and treated in humanitarian emergencies*; Karolina Himanen – is investigating *the relationship between female genital mutilation or cutting (FGM/C) and incontinence and care practices, in the particular context of humanitarian aid*; and Elina Sirén – is looking at the *intersections of violence and incontinence in the lives of persons with disability in humanitarian spaces*.

ONGOING OPERATIONAL RESEARCH

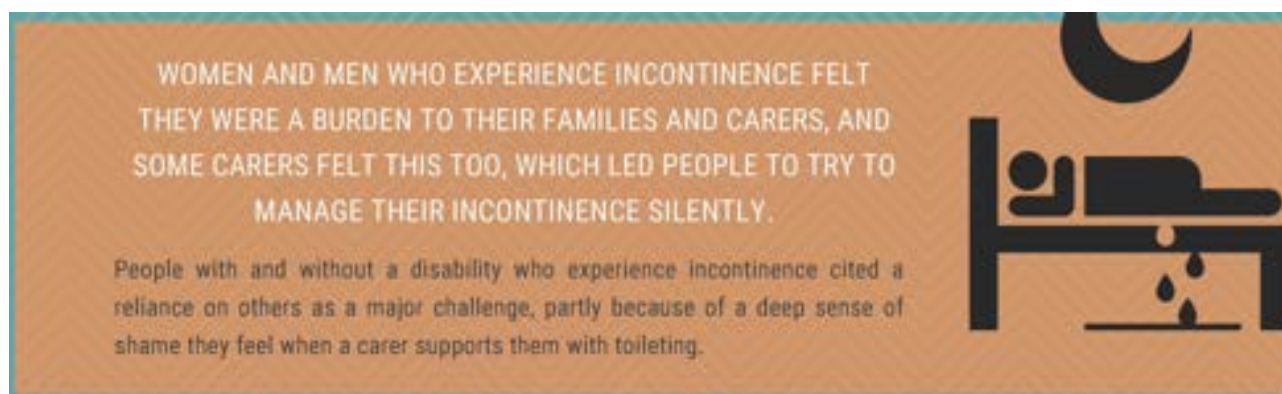
OXFAM and HelpAge have also been undertaking some operational research on *home-based sanitation and home-based care for people with mobility issues who cannot use latrines*. This includes learning in IDP camps in Myanmar, near the border with Bangladesh.

WATER, WOMEN AND DISABILITY STUDY, VANUATU - WORLD VISION AND LSHTM

World Vision and LSHTM and partners, undertook an important and large-scale study in 2019, on MHM and incontinence for people with disabilities across Vanuatu. Vanuatu is an island state in the Pacific, affected by natural disasters. The case-control study, asked similar questions to 1,516

participants, covering people with and without disabilities, so this resulted in a range of useful data and qualitative findings. Refer to **Annex III.2** - for more details and key points from the learning from this study.

FIG 9 - EXTRACT FROM THE VANUATU PEOPLE WITH DISABILITIES RESEARCH INFOGRAPHIC



(Credit: LSHTM and World Vision, 2022)

ELRHA / HIF RESEARCH ON INCONTINENCE IN HUMANITARIAN CONTEXTS

ELRHA's Humanitarian Innovation Fund (HIF), funded three research studies focusing on people living with incontinence in humanitarian contexts. These studies are important studies, in relation to incontinence in humanitarian contexts, because these are the first studies, which have looked at this issue of incontinence specifically in humanitarian contexts. The three studies included:

LED BY OXFAM-GB

Learning from older people: Barriers to inclusion of older people with incontinence in humanitarian contexts in humanitarian programming – with particularly interesting learning from Malawi and Ethiopia, being related to: a) adding questions into quantitative assessment surveys; b) feedback visits integrated into the research process; and c) involvement of a mental health specialist in the process.

LED BY RESEARCH AND GRANT INSTITUTE OF GHANA (REGIG)

WASH programming for women with obstetric fistula induced incontinence in Ghana – with particularly interesting learning on: a) the psychological challenges and stigmatization; b) gaps in WASH support for women with fistula; and c) gaps in operations for fistula.

LED BY LEEDS UNIVERSITY / UNIVERSITY OF WESTERN AUSTRALIA

Understanding the experiences of children with incontinence and their caregivers – with particularly interesting learning experience in incontinence from Uganda and Bangladesh on: a) the development and



Participatory exercise undertaken with older people to assess options for non-food items, most useful to help them manage their incontinence more effectively - Undertaken during the OXFAM-led research, 2018-2021

(Credit: M. Farrington/OXFAM/2021)

use of a participatory tool for children; b) frustrations for parents; and c) the impact of inappropriateness of WASH facilities.

For partners, more context for each research, more details of the interesting learning from each research and links to published findings, refer to **Annex III.2** and **Supporting document 2**. A number of photographs and quotations from the studies above, have also been incorporated into other sections of this mapping report.



Delighted woman who has undergone fistula surgery, Ghana

(Credit: Research and Grant Institute of Ghana/2021)

“One of my aunts used to bake bread, so I used the flour sack as pad. I washed it with Dettol and power zone. When it dries, I folded them into a bag. That was what I was using till I received diapers in the form of a pant from some white visitors who came to the Tema harbour”

Woman who has undergone fistula surgery, Ghana
(Quote documented by Research and Grant Institute of Ghana/2021)



Children's drawings on living with incontinence, using the participatory Story Book methodology, Bangladesh: Cox's Bazar Refugee Camp

(Credit: World Vision Bangladesh/October 2021)

5.1.6

Innovation, supply and logistics

A range of proactive work is ongoing, related to product selection, innovation and supply. The following are some of the key examples. These are expanded further, in three case studies in

Supporting document 1:

| CS-GHA-A | CS-GHA-D | CS-GHA-I |
|-------------------------|-------------------------------------|--|
| Regional Syria Response | Vanuatu | Global |
| Loving Humanity | World Vision | UNICEF, WHO |
| Washable pads | Supporting people with disabilities | Supply and innovation – including in Ukraine |

ON-GOING OPPORTUNITIES FOR ALL – TO LEARN MORE ABOUT INCONTINENCE

NCA on-line training on MHM and incontinence

NCA has developed an online training on **MHM and incontinence**, which is available online to any participants. This can be accessed through: <https://fabo.org/nca/NCAWebinarSeriesMHM>

WHO training in absorbent products for incontinence

A series of MOOCs, have also been prepared to support the release of the new **Training in Assistive Products (TAP) series**, prepared by WHO, to introduce assistive products from the Priority Assistive Products Lists (APLs). One of these MOOCs is on the subject of **Absorbent Products**, which are used for the management of incontinence. These MOOCs are free to participate in and can be undertaken on a range of different subjects. <https://www.who.int/news-room/events/detail/2022/11/10/default-calendar/launch-of-who-training-in-assistive-products>

INNOVATION, SUPPLY AND LOGISTICS EXAMPLES

ASSISTIVE PRODUCTS FOR PEOPLE WITH DISABILITIES – UNICEF PRODUCT INNOVATION CENTRE

Description

UNICEF Supply Division has over 500 staff and they procure over USD 7.2 billion worth of products each year. The products can be purchased by UNICEF, WHO and other UN agencies, governments, NGOs or universities. They are sold on a non-profit basis, with only a 3-4% handling fees added on, for the costs of managing the procurement (except for government and UN agencies).

UNICEF is working to ensure assistive and

inclusive supplies are affordable, of good quality and accessible worldwide. This includes through introducing new assistive products to programmes, and increasing advocacy efforts to gain a global consensus for assistive technology. The UNICEF Product Innovation Centre, in the UNICEF Supply Division, in Copenhagen, is led by Dennis C. Søndergård. In addition, UNICEF undertakes scale-up projects for products in high demand - with incontinence, inclusive education, Digital AT and

vision products, currently in the pipeline. These products are at different stages of development, in the process of identifying suppliers and setting up long-term supply agreements. Key work that this team have been undertaking, includes:

Coordinating the development of an incontinence kit

Muhidin Abdulla has been leading on the development of this kit. It will be taken through a process of trialing, refinement and scaling, before being added to the UNICEF supply lists. At the moment, a list has been identified, with some inputs from the informal email group, which includes: Incontinence pads (Diapers); Underwear; Hand held urinals / Urine collection products; Pull pads; Night pads; Soft cotton material; Absorbents; Bottom wipes; and a Pad for mattresses. This kit is still in the early stages of development.

Hygiene kits for people with special needs in Ukraine

In addition, some items for people with incontinence, have already been included in hygiene kits being distributed in humanitarian responses. This includes, through the distribution of small hygiene kits for people with disabilities in Ukraine, known as Hygiene Kits for 'People with Special Needs'. There are four items in the kits, including diapers, mainly for older people and adolescents and bed pads.

38,000 hygiene kits have been sent to Ukraine for people with disabilities for children and adolescents with disabilities. Information was not yet available at the time of writing this report, on how many have been distributed, or feedback from the beneficiaries.

Disability – designing accessible toilet slabs

A research project is being run by Esther Shaylor and Emma Tebbutt, working across sectors, involving Education, WASH and Disability. There is a disability add-on for the latrine slab, and scaling is being undertaken by including 10% of the slabs sent to humanitarian contexts, with the add-ons. One kind – fits on slabs during construction, and the other can be fitted over an existing toilet slab. One is more expensive for shipping than the other. The more volume of products requested, the cheaper the product becomes.

For more information see:

<https://www.unicef.org/innovation/assistive-products-and-inclusive-supplies>

https://www.unicef.org/innovation/sites/unicef.org/innovation/files/2022-03/Assistive-products-for-emergencies_0.pdf

The longer case study **CS-GHA-I - in Supporting document 1** – also provides more details.

ASSISTIVE PRODUCTS LIST – INCLUSION OF ABSORPTIVE PRODUCTS – WHO AND UNICEF

The WHO ATA team, receive priorities for assistive technologies and provide guidance to member states, and supporting member states which are struggling. WHO's role is the development of normative documents and the assistive products list, as well as the development of tools and resources. They work through regional advisors and through some links to countries and sometimes through WHO Directors. Plus, they undertake some pilots and other activities and support the development of some technologies. Activities they have recently been involved in, related to incontinence include:

Products in the Priority Assistive Product Lists (APL):

- There are currently 6 products in the APL lists, which are linked to disability-related challenges, identified through the Washington Group questions. Incontinence fits in self-care. The items include: a shower chair, a toilet chair, absorbent products and catheters. There are several lists.
- **APL-2.0 list** – Includes four groups of health products, which should be available in all countries. These include 50 products, which are identified as priorities. These are in addition, to long-standing items related to diagnosis and medical devices. Some products are new to the 2.0 version. Experts and advocates can argue for other items to be added. Recently, wheelchairs have been added.
- **ATP-6 list** – This includes assisted technical products, purchased through the WHO procurement system.
- **ATP-10 list** - Covers medical trauma – including toilets and commode chairs for hospital use, not for personal use. The broader list, goes to absorbent single-use products, in medical facilities. Plus, it includes assisted products used by the Ministry of Health (MoH) for people who are displaced within a country, which includes catheters and absorbent products.

- **DG Catheter list** - Innovation is currently being undertaken by Australia for this list, after a lot of research on the use of self-inserted, intermittent catheters.

Assisted products specifications:

- This includes specifications for 26 of the 50 products – incontinence pads and underwear, can be found on pp27-36 and toilet and shower chairs on pp101-107: **World Health Organization. (2021) Assistive product specifications and how to use them.** World Health Organization. License: CC BY-NC-SA 3.0 IGO, <https://extranet.who.int/iris/restricted/handle/10665/339851>

MOOC on Absorbent Products - Training in Assistive Products (TAP):

- This Massive Open On-line Course (MOOC), has been prepared, including an Absorbent Products Module. This training was launched in Nov 2022. The training will now be available in a 2-week loop. Other modules will also be released after this. There will also be a catheter module, at a later date. More info can be found here: <https://www.who.int/news-room/events/detail/2022/11/10/default-calendar/launch-of-who-training-in-assistive-products>

Support to Ukraine:

- WHO in Ukraine, has supported products for the first time, and a few tweaks have been made to the products, for the Ukraine contexts. This includes adding self-lubricating catheters, to the catheter and urodynamics kits, including toilet and shower chairs for community use and also considering incontinence. On the ground, training has been provided through TAP, for the workforce of the Ministry of Health, who have been mobilized. The training is being undertaken in 10 health facilities and monitoring and learning activities, are planned for the end of the process.

TRAINING OF CARERS, DEVELOPMENT OF RE-USABLE PRODUCTS AND LOCALLY MADE TOILET CHAIRS – WORLD VISION AND MAMA'S LAEF, VANUATU

Vanuatu is an Island state in the Pacific, which is affected by natural disasters. World Vision and LSHTM and partners, undertook an important study in 2019, on a large-scale on the experiences of people with disabilities across Vanuatu, on MHM and incontinence. 1 in 3 people with disabilities face incontinence in Vanuatu, and more often as people age and as a result of child-bearing.

The work shared in this case study, followed the research fundings in 2019, after they realized that people only felt they had two strategies to manage their incontinence – adult nappies and to limit their intake of food and water. This resulted in limiting their participation.

The project undertook a range of activities, to find solutions for the people with disabilities living with incontinence:

- **Carers training**

They developed a carers package for people with disabilities and their carers, so they will have other strategies. This was called *“Lift ‘em up life”* – which means improving life of people with disabilities and their carers. These were not in-depth modules, but are touching on incontinence.

- **Guidance documents**

For these, they were aiming for simple one-pagers. In the carers training, they are promoting 3 options: a) Washable/reusable pads, to protect the bed from incontinence – for people who are mobile; b) Portable toilet chairs – for people who can use their upper bodies; and c) Washable/reusable incontinence underwear.

- **Worked on developing incontinence pads**

The pads developed, are re-usable with 2 sizes for women and 2 different ones for men. These can be used by people who are still mobile and would like to do activities – but do not know where the toilets may be and they are slow with their mobility. Mama's Laef - <https://www.mammaslaef.com/what-we-do/>

- **They have also have developed a mattress protector**

This is made from recycled rice bags, with an absorbent layer on top, with the rice bag on the bottom (see the photo below). It can be used on a bed or on the floor. Some of these also have rings on the sides, so that they can be tucked under the bed, to hold it in place.

- **They have also made wooden toilet chairs from wooden pallets**

They were made locally made and sustainable products, using recycled pallets, using wooden timber and 3 coats of marine varnish and then sanded. The recycled pallets were sourced at 5 AUD, but there may be opportunities to also use other wood. The chairs were made by a local carpenter and purchased for 100 AUD. They made them suit the needs of each user. Some were made low, so they were easy to get on to, some were at a height the person can slide directly from the bed, and most had an anti-tip mechanism and 2 arm rests. For one woman, who slides directly from her bed, the seat was made extra wide, and with no arms on the chair.

Kalmark is an elderly man who has been unable to walk since experiencing a stroke two years ago. He was cared for by his wife who passed away earlier this year. He now lives alone in Eton Village.

“This chair has been a blessing for our father. He was so surprised and grateful to receive this chair and it has improved his happiness with life.” “He no longer has to drag himself to go to the toilet on the ground behind the house and he is also using the chair to exercise when he is at home alone during the day. Since the death of our mother, it has been very hard for him as she was the one who cleaned up after him.” “This chair has given him back some privacy and dignity with toileting.” “Thank you”.

Penita Kalmark's Daughter
(Credit: Allison Coleman / World Vision, Vanuatu / 2021)



- **They have also developed a WASH mitt**

You can slide your hand into the mitt, so that you can easily wash off urine or faeces from your or the skin of the person you care for, without touching it with your hands.

These experiences, have also been documented in a briefing note and a number of simple and clear posters: https://drive.google.com/drive/folders/1zJXia_gAe3xkW9TbMDL_b8vJ6s8avE-9?usp=share_link



WASH mitts and mattress protectors made from rice sacks

(Credit: Allison Coleman / World Vision, Vanuatu / 2021)

A short video has also been prepared of one of the beneficiaries of the World Vision and partners work in Vanuatu. Shirley is a 14-year-old girl, who was unable to easily go to the toilet, due to her mobility difficulties and the distance to the toilet. She now has one of the portable toilet chairs to use inside her house, so she can be independent and safe when toileting: <https://youtu.be/oYFAWw0UCiw>

been put into a presentation. This is called **“Making Inclusion Meaningful”** and was presented at the Vanuatu Health Research Symposium 2022. Allison won an award for this presentation, which is fantastic: <https://youtu.be/fiVYJWgoYQQ>

See case study **CS-GHA-D** in **Supporting document 1** - for more information.

A video on the support to construct VIP latrines, for people with disabilities in Vanuatu, has also

WASHABLE/ REUSABLE INCONTINENCE PADS FOR REFUGEES IN MULTIPLE COUNTRIES – LOVING HUMANITY 2014 - 2022

The charity, Loving Humanity (LH) was founded by Amy Peake and provides menstrual hygiene products and incontinence pads and underwear, to some of the most disadvantaged people across the world, particularly people in poverty and refugee situations: www.lovinghumanity.org.uk

at the time, and bedwetting was a major problem, amongst the children coming over from Syria. And a particular problem, was due to the freezing cold in the desert at night. She had learnt that 75% of the children (1 to 18 years), had been bed-wetting, due to the trauma of what they had seen.

Amy became aware of the issue of incontinence, whilst working in their factory making menstrual pads in the Za'atari refugee camp, for Syrian refugees in Jordan. UNHCR made her aware of the issue, in 2014, a few years after the start of the Syrian war, saying incontinence was a big problem in the camp. There had been a huge influx of refugees

After a while, it became apparent that this was costing the UNHCR a fortune, and they completely stopped supplying products at the Za'atari camp. This meant that families, found it almost impossible to keep everyone clean. Amy was able to source washable/reusable products, from a manufacturer in Turkey, who

made waterproof pants, and in particular the cotton inserts. These were initially made in the Syrian refugee camp in Jordan and supplied to the refugees.

But due to the politics of the situation, she, then had to move her factory out of the camp to a compound near Amman, where she then employed 5 Iraqi women to make the products (menstrual pads and nappies). But again, due to the humanitarian politics of the situation, Amy was not able to distribute these products to many of the children who needed them. This was because the camp had initiated a treatment program for the traumatized children, but they were not allowed to enroll in it, if they used these products.

As a result, to keep the factory going, they decided to export the products. And they now export to a care home in a township in Cape Town, South Africa, and export, washable menstrual pads to Burundi and Sierra Leone, and baby nappies to Palestinian camps in Jordan.

Factories making washable nappies and pads in 2022:

Loving Humanity now has factories in Jordan, Kenya, and Iraq, and plans to open more facilities soon. They also have a warehouse in Radstock near Bath in the UK:

- # **Jordan** – This factory makes washable nappies and washable pads
- # **Kenya** - 7 micro-factories/workshops, 5 are implemented and 2 are going into operation. These make disposable pads, with raw materials sourced from Europe.

- # **Iraq** – One factory that makes disposable pads. The management of which is split between Loving Humanity and another UN agency.
- There is also a plan to set up a factory in Sierra Leone for washable pads

Opportunities for other humanitarian actors to also distribute the washable/reusable products:

Loving humanity has 9 patterns for their incontinence underwear / nappies for babies (3 designs for babies, 3 for children, and 3 for adults). They distribute the products (washable incontinence underwear, nappies and pads) which are free. And they are always trying to find new people who need the products. So, this opens up the opportunity for other humanitarian actors, to source these products from Loving Humanity.

The main aim at Loving Humanity is very simple, they *'Just want to get nappies and pads on people'*. This is so that people living in difficult humanitarian situations, such as refugees and people living in poverty, can live a dignified life.

To see two videos, with feedback from a beneficiary talking about the Loving Humanity babies' nappies and also a video of the menstrual hygiene / stress-incontinence washable pads and Loving Humanity colleagues who run the micro-factory in Jordan. This is as well as a flyer of the Loving Humanity washable products - see: https://drive.google.com/drive/folders/1hXRYlim8qB0SUotkv1hKoZftTQTzy661?usp=share_link

See case study **CS-GHA-A – Supporting document 1** – for more information.

URINARY MANAGEMENT PRODUCT TRIAL – MOTIVATION AUSTRALIA EVALUATION REPORT – JULY 2016

Motivation Australia (MA) and the Fiji Spinal Injuries Association (SIA), initiated a Urinary Management Products trial, in close collaboration with the Fiji National Urology Centre (NUC) and the National Rehabilitation Hospital (NRH), both of which are departments of the Ministry of Health and Medical Services (MHMS). The trial was funded by the Australian Government, the June Canavan Foundation, and the Clare Murphy Fund. Australian suppliers Paralogic and Coloplast, donated some of the products.

Trial objectives:

- To confirm the components of affordable monthly packs, offering three Urinary Management options (external, indwelling, clean self-intermittent), suitable for the Fijian/Pacific context.
- To draw conclusions regarding effective provision of UMPs to individual users, that could be applied in a range of Pacific Region contexts.

- To identify sustainable funding options for procurement and provision of UMPs for Fiji and potentially other Pacific Region Small Island Nations.

A wide range of detailed findings were shared in a trial report, which can be requested through Motivation Australia: <https://www.motivation.org.au/our-work/pacific-region/fiji/urinary-management-products-trial-underway/>

LOVING HUMANITY

WASHABLE INCONTINENCE PRODUCTS & BABIES NAPPIES

Loving Humanity manufactures washable adult incontinence pads, adult incontinence underwear and babies' nappies in our Jordanian micro-factory, where we employ 5 Iraqi refugees. We seek new distribution partners in the humanitarian sector who work to alleviate the suffering caused by incontinence. If you might be interested to distribute our products to people affected by humanitarian contexts, please get in touch.

Contact: [Amy Peake](mailto:amy@lovinghumanity.org.uk) - amy@lovinghumanity.org.uk +44 7788 202 069 - www.lovinghumanity.org.uk











This is the smallest size nappy for a newborn
They have a cotton three-fold insert

There are 9 sizes:

- 3 baby sizes - nappies
- 3 children's sizes – incontinence underwear
- 3 adult sizes - incontinence underwear

These are washable menstrual pads / stress incontinence pads with shields (red) and liners (white)

They can also be made in different sizes as required

The white bag holds 3 shields (like the red one) and nine inserts for changing

The green bag is waterproof for holding dirty inserts before washing.

CONTINENCE ADVISORY WEBSITE - UNIVERSITY OF SOUTHAMPTON AND UNIVERSITY COLLEGE LONDON (UCL)

This is a very useful website on continence products, that is being managed by the University of Southampton and University College London (UCL). It is more high-income country focused, but is still very useful for humanitarian and lower-income contexts, as well. The people managing the site, get a weekly report about who has accessed it. This is usually about – one third UK / one third US / one third, the rest of the World, of which, half are from Africa and half from Asia. Therefore, if internet access in humanitarian settings is available, then people there could also access this site, although they may have limited access to some of the types

of products shown.

The sites have useful tips and feedback that users have given on different products, quite a bit of which will be transferable across contexts; although people in the lower income and refugee contexts will face additional challenges.

Video on the products advisor website: <https://www.youtube.com/watch?v=6qgoogfotSE&t=9s>
The website: <https://www.continenceproductadvisor.org/>

WHO FUNDED RESEARCH INTO ABSORBENT WASHABLE PRODUCTS - UNIVERSITY OF SOUTHAMPTON

The exploratory study on re-usable incontinence products:

- The University of Southampton is undertaking a WHO-funded exploratory study, looking at the provision of absorbent washable products. The research is taking place across 3 different countries - Romania, India, and Papua New Guinea. There are three country partners - Motivation Romania, Mobility India, and Eyecare in Papua New Guinea.
- This project is part of the WHO's Global Cooperation on Assistive Technology (GATE) Initiative / theme, which states that everyone in the world should have access to these technologies if they need them. These aims are on a huge scale and could include 2 billion people. It puts sustainability at the heart of the program.
- WHO identified 50 essential assistive technologies, one of which was washable/reusable continence products, with others being items such as walking aids and hearing devices. They also identified 5Ps that were important in making this possible, which were, People, Products, Provision, Personnel, and Policy. All of which could also be barriers to distribution and use.
- WHO sent a range of products to people involved in the study, which included children (over 6yrs) and adults. They talked to local providers (who

were not necessarily trained in incontinence), about their views and asked them to record the views of the people using the products, such as what they liked and disliked about them.

- People recruited were mainly spinal cord injury patients and came from very different contexts. For example, some already had experience of using disposables (in Romania), whilst others in rural India, were using rags. But initial feedback is that they were all fascinated with the washable/reusables they had been given, although the products provided had only been given to small numbers of people.

The main barriers to the research and access to the products:

- **Research:** Translation issues and getting hold of people. But people were enthusiastic about the topic, which had been of concern before the work began. The researchers were also worried about people not wanting to talk about incontinence, and potential cultural barriers. But these were less than they thought. They wanted to talk about it.
- **Products:** These were the main issues for the project. Particularly, sourcing the products and getting the products to the people that need them.

TROLLEY FOR OLDER PEOPLE TO CARRY NFIS INCLUDING INCONTINENCE PRODUCTS - NRC, UKRAINE

The Norwegian Refugee Council (NRC) team in Ukraine, introduced the use of shopping trolleys to help older people collect their non-food items (NFIs), which included incontinence pads, as well as other products. The idea was initiated, because it was realized that the weight of the NFIs, would be very difficult for older people to carry. They were also used in Mariupol, during the middle of the conflict. The shopping trolley could also be useful for other people, such as people with disabilities,

women who are pregnant or carrying a small child, or other people who struggle to carry heavy items.

Also see case study **CS-NCA-D** – in **Supporting document 1** - on the work of NCA in Ethiopia and the assessment process they are undertaking, to support the IOM in incontinence innovation product-related research, funded by Innovation Norway.



The Kravchuchka (shopping trolley) in Ukraine

(Credit: Gary Campbell / NRC, Ukraine / 2021)
(Shared by, NRC Logistics team member,
Ukraine, 2021)

Experience in Mariupol - showing usefulness of the shopping trolley:

"When it became clear that it was impossible to stay in the city, businesses left the city, leaving their warehouses and stores to their fate. Thanks to this, many citizens escaped hunger, cold, and thirst. It took some ingenuity to transport such cargoes in the absence of any energy in the form of light, gas, and fuel. In the beginning, people used simple supermarket carts, but because the roads were bombed and in terrible condition, the wheels just flew off as they went. No matter how much the residents of Mariupol repaired these wheels, it was useless. One neighbor pulled a construction wagon out of a burned-out basement, but its wheel melted. People took the abandoned bicycles, tied the load with a rope, and dragged it along the ground. At this point, when I say cargo, I don't mean humanitarian aid, it could be anything from water bottles to corpses. Mariupol residents even used children's bicycles and toys - anything with wheels".

"When the hot phase ended and people finally began to receive humanitarian aid, it was only in one place in town, practically on the outskirts. Many people came on foot from the other side of town to get this aid, but ended up with almost nothing, because they couldn't carry everything to their house. They tied ropes to boxes and dragged them along the ground. They threw away some items (soap, shampoo, water), to make it easier to drag. The Kravchuchka (shopping trolley) was worth its weight in gold in Mariupol".

5.1.7

Monitoring and evaluation

Not much information was found on monitoring and evaluation-related, existing good practices, although a number of projects have already had evaluations and others, are planning to undertake post-distribution monitoring, for distributions currently being made, in Ukraine.

A few examples where shared:

- NCA has an incontinence-related indicator in the Norwegian Ministry of Foreign Affairs (NMFA), SPA - see below

- UNICEF has been looking at possible indicators for incontinence efforts, being undertaken at present in Ukraine. These were still under development, at the time of this mapping process.
- It was reported, that UNICEF has been doing some mapping of humanitarian WASH, trying to include an indicator showing satisfaction levels of the facilities. Examples of this work, could be seen in the Rohingya response, supported by REACH.

Who should own the indicator and the funding?

The assistive devices / incontinence items are not reported under health, but under protection outcomes, or in cross-cutting related to age and disability. The question is where should we put the indicator, if there is joint coordination? This also relates to where does the funding come from, who owns it and who manages the funding? The risk is that some sectors may consider they have lost a key role if one sector owns and manages the funding?

One suggestion made is that it would be positive if WASH, protection, health, can have a joint indicator and each can try and get funding from their different sources to support the joint indicator – possibly focusing on different kinds of items.

TABLE 3 - NCA INDICATORS ON MHM AND IN RELATION TO INCONTINENCE - NORWEGIAN NMFA, SPA

| | |
|--|---|
| <p>Output 3.4</p> <p><i>Women and girls of reproductive age, and women, girls, men and boys with incontinence, have access to appropriate hygiene supplies and WASH facilities that support their dignity and well-being.</i></p> | <p>3.4.1: # of targeted women and girls of reproductive age with access to appropriate materials and information ensuring dignified menstrual hygiene management</p> |
| | <p>3.4.2: % of women and girls of reproductive age who are satisfied & feel safe when using the WASH facilities during menstruation</p> |
| | <p>3.4.3: # of people with incontinence with access to appropriate materials, facilities and information to manage incontinence in a dignified manner</p> |

The challenges of where to locate an indicator, when there are responsibilities across sectors, was also highlighted by one respondent. This was

while discussing the same challenge, related to indicators and funding related to assistive devices, for people with disabilities.

5.1.8

Opportunities for learning from MHM and other actions

A number of examples were also shared, where lessons, might also be useful, for the scaling up of incontinence efforts. Lessons are discussed and links provided, for the following learning in **Annex III.4** - covering the following:

- **Annual MHM/MHH in Schools webinar event**

This kept attention on MHM/MHH in schools, and offered opportunities for both academics and practitioners to share their learning.

- **Progress on MHM in humanitarian response**

It has taken over 2 decades, to get to the point, where there is now more attention increasing on MHM in emergencies, including having a dedicated toolkit, developed with cross-sectoral responsibilities.

- **Establishment of the MHM in Emergencies (MHMiE) working group (TWG)**

The MHMiE TWG, was initially set up, to coordinate across 4 main UN agencies with responsibilities in the area of MHM in emergencies – UNCHR, UNFPA, IOM and UNICEF. It also has other active INGO members and members across WASH, health, protection and GBV sectors. This mechanism aims to encourage commitment within the UN agencies. They developed a strategy and are working on tools, quality issues and operational procedures. Coordination led by UN agencies is positive, in terms of encouraging commitment for action in humanitarian responses, but there could also be risks for sustainability, if there are changes in key staff.

- **Research into MHM for girls with learning disabilities in humanitarian contexts**

A range of learning on how girls with learning disabilities are overlooked for support on MHM, in both development and humanitarian contexts and the development of appropriate methodologies to respond to this issue, also may provide useful lessons for supporting people with learning disabilities in incontinence. For links to the *Bishesta* Campaign in Nepal and the *Veivanua* campaign in Vanuatu, which relates to emergency contexts, refer to **Annex III.4**.

- **UK Institution of Mechanical Engineers (iMechE) – incontinence technology focused conference**

This is coordinated through a partnership between Leeds University, University College London & Southampton University in the UK – This conference brings together experts working on continence technologies, and includes a panel of people with incontinence to hear the opinions of users. Last year, the event was held on-line, which allowed more participation from people in lower- and middle-income countries. The conference, provides opportunities to learn about the latest products and developments in continence care.

- **Tampere University organized conference on sustainable continence products, 2022**

Likewise this conference, also offered opportunities to learn from continence specialists, as well as people living with incontinence. Both conferences, however, require significant time and resources to organize.

5.2

Global Humanitarian actors (GHA) – Humanitarian responses

5.2.1

Overview of GHA humanitarian responses

This section, provides an overview of humanitarian action in incontinence, in different countries. The details in these tables, include actions by other global humanitarian actors (GHA), other than NCA, with links to earlier case studies from NCA, to provide a more complete overview. Some of the examples in this table are also covered in more detailed case studies in - **Supporting document 1**.

The dates in the table, indicate the approximate period, during which the incontinence-related actions were undertaken, unless the exact dates were not known. In this case, 2022 has been entered as the date the case study was provided.

The case study examples have been separated into a series of tables focusing on:

EARLY ACTION

UKRAINE

GBV AND FISTULA

HEALTH AND DISABILITY ACROSS CONTEXTS

VARIOUS

EXAMPLES - HUMANITARIAN RESPONSES ON INCONTINENCE – EARLY ACTION



COUNTRY: PAKISTAN EARTHQUAKE RESPONSE 2005/6



DETAILS:

SUPPORT FOR ACCESSIBLE TOILETS, COMMUNE CHAIRS, URINALS AND BED PANS

In OXFAM's humanitarian response to the Pakistan earthquake response in 2005/6, efforts were made from the first week of the earthquake, to integrate considerations for people with disabilities into the WASH response. This was a learning process, and the efforts proved that it is very possible to integrate considerations for people with disabilities, right from the start of an emergency. It is just about mindset and believing that it is our responsibility and everyone has a right to dignity. Steps taken:

1. The first steps taken were to double the size of one unit, in some toilet blocks, constructed in temporary hospitals and camps

2. Next removable commode chairs made locally using wood and varnish, which were placed over squat holes in some toilet units

3. Consultation was also undertaken with people with disabilities and their families, and they requested commode chairs to be used in their shelters, so some of these were locally sourced

4. In addition, in response to the Public Health Engineering team, questioning how people who were bed-bound due to injury during the earthquake, were managing to go to the toilet; urinals and bed pans were also sourced and purchased locally.



Bedpan and male urine container - Female urine containers were also available in Pakistan
Photos: Saira Raza



This wooden seat was used in a unit for disabled persons (one for male and for one female) in a medical camp in response to the Pakistan earthquake. It was varnished for easy cleaning and had strong arms and back. The users reported finding it easy to use.



One model of the commode chairs provided to disabled people in the IDP camps in Pakistan
Photo: Saira Raza

(Credit: Saira Raza/OXFAM/2006)

These extracts were taken from the OXFAM-GB Technical Brief, first published in 2007: **OXFAM-GB (2007) Excreta disposal for physically vulnerable people in emergencies⁸⁸**.

This technical brief was prepared by Sarah House, the Public Health Engineering (PHE) Team Leader, of the team who undertook this work, with inputs from Bibi Lamond, Saira Raza and other Pakistan PHE and PHP team members at the time, as well as Andy Bastable globally.

The above examples, were not perfect, with challenges with the commode chair, being that the pot was quite shallow, so the user was sometimes splashed on use. In addition, the space in the unit, with the wooden chair with a hole in it, was too small and users with plaster on their legs, could not close the door. Also, there was no splash guard to protect the person's legs from being splashed, as urine or faeces hits the pour flush pan.

It is recommended by the authors, that this case study, should be considered when reflecting on the action, that is, or is still not being undertaken today by humanitarian actors, to support older people and people with disabilities. The question to be reflected on, is why have we, as the humanitarian WASH community, not worked on this issue before, considering that this particular case study, was implemented 17 years ago? It is hoped that this will promote increased attention and effort in this area, going forward.

 COUNTRY: REGIONAL SYRIA RESPONSE 2021

CASE STUDY: CS-GHA-A • ALSO SEE: CS-NCA-A

 DETAILS:

PROTECTION AND WASH SUPPORT IN THE REGIONAL SYRIA RESPONSE

A number of different actors have provided incontinence-related support in the Regional Syria Response. Some of these actions are covered in other sections and in:

- **Loving Humanity**

Local production of re-usable incontinence pads and nappies for babies – initially provided to the Za'atari camp in Jordan in 2014 – see **Section 5.1.6** and **CS-GHA-A – Supporting document 1**

- **Humanity and Inclusion**

Supporting people with spinal cord injuries -
CS-GHA-E – Supporting document 1

- **NCA support**

Support for older people living with incontinence in Syria and Lebanon – see **Section 4.2.1** and **CS-NCA-A – Supporting document 1**

UNHCR SUPPORT FOR PEOPLE WITH DISABILITIES IN SYRIA CAMPS, 2021

The following information was provided in the UNHCR Annual Report for 2021.

The needs of 227,239 persons with disabilities were addressed in 2021. Around 10,700 individuals received mental health and psychosocial case management services, 93,749 vulnerable people received general and medical in-kind assistance, and 18,124 disabled people received adult diapers.

The need for adult diapers, was identified by UNHCR and its partners, as one of the most pressing needs, with a high number of marginalized older persons and persons with disability, requesting the service. The situation is compounded by precarious living conditions, the high cost of adult diapers and the unavailability of the items in Syria.

The home-based programmes, reached 1,804 people with disabilities and 6,265 older people and their caregivers. Specific home-based rehabilitation and training programmes, to assist persons with disabilities and older people, were also carried out during 2021 and were recognized a best practice in the region.

UNHCR and its partners additionally conducted three, 'Training of Trainers' for 70 partner staff on mental health and psychosocial support case management, support to older persons and psychological first aid. Additional training was conducted to 400 partner staff, on individual and group counselling; problem management; caregiver skills; applied advanced behaviour skills, programme analysis, basic interventions for persons with disabilities and psychomotor interventions.

NOTE – However, this also seems to be a case of losing staff memory, probably with turnover of staff, of what was done previously, as Loving Humanity had set up a manufacturing facility in the Za'atari camp in 2014. But due to politics in the camp, had to move the manufacturing facility to Amman. And then was not able to supply the products to people in Za'atari camp, as then they were told they would not be eligible for MHPSS support. So, they took the products elsewhere.

 **COUNTRY: IRAQ**

CASE STUDY: CS-GHA-A • ALSO SEE: CS-NCA-A

 **DETAILS:**

MSF - PSYCHOSOCIAL SUPPORT AND POSITIVE PARENTING, RELATED TO CHILDREN WHO ARE WETTING THE BED

In Iraq, there was a lot of bed-wetting. It was reported that MSF undertook outreach for psychosocial support and positive parenting techniques, to try and help their children from wetting the bed. They also used this process, as potential screening for other issues.

See also the NCA case study – **CS-NCA-B – Supporting document 1.**

 DETAILS:

IRC & IFRC – WASH RESPONSES SUPPORTING CHILDREN WETTING THE BED

Greece – IRC

In the early stages of the response, people were on the move

They were being pulled from the beach and were on the move in Lesbos and other places. They often arrived with nothing. There were toilets and hot showers, which they could use within the first 24-48 hours, before moving on and there were some heating and warming rooms. There were quite a lot of actors who were exceptionally new to such responses, as they had never done this before, so they thought more outside the box, than the usual humanitarian agencies. Many supplies were also donated, including items were given from hotels, so there were things like very small bottles of shampoo, etc. IRC set up a hygiene kiosk, so people could ask if they can have items and if we had it, the team would give it. The taking of products at this stage, was self-regulating, because people were on the move, so they only took what was required to meet immediate needs.

During the later stages, IRC gave vouchers to vulnerable adults and children

They asked people what was needed and gave them the opportunity to purchase them. They set up a hygiene hub and people could come to see the staff in the kiosk and staff could also point them in the

right direction also, to get more support. The kiosk was put outside the women's toilets. Through this process, the incontinence issue came up – children were wetting the bed, including older children, not only toddlers. They had fled trauma in Syria and faced a hazardous journey in small boats. Also, older people and people with disabilities, were also struggling with this issue. People also knew about incontinence products, so knew to ask for them.

At the beginning, IRC did not have products. They then purchased them in response to requests. It is very much a dignity issue and keeping bedding dry was also a major problem. This included having enough water day and night and also an ability to dry the bedding, in the middle of winter. This posed a big problem for parents. Later in this response, there were launderettes set up, but especially in the early days, laundry was big challenge.

The IRC also prepared an excellent Technical Brief⁴⁴, on how to set up a Hygiene Kiosk, with lots of practical details included, so that other teams could follow it step-by-step. This even included floor plans for the kiosk, information on queues, registration documents, record keeping etc.



This was one of the hygiene kiosks set up in Greece by the IRC

(Credit: IRC / Greece / 2016)

Greece - IFRC:

People were traumatized when they arrived in Greece

The IFRC provided WASH items to the parents of children, who were wetting the bed due to trauma. The team had to justify to include incontinence in their budget and plan of action. They had become aware of this issue, when the winter came and the parents were struggling to dry the bed sheets. It was the HPs who had this knowledge and identified the problem.

They had a lot of problems with the laundry rooms

The problem was that if it got colder, it was not possible to wash and dry bedding etc. They had washing machines, but not driers, so, there was a problem for drying items. And also, households had problems with not having enough tokens for the laundry. Mothers were saying this was not enough, when washing bedding and clothes. There were also some problems with laundry detergent, which were related to its quality. There were also problems with the waste, which was not well organized.

Initially MHM-awareness sessions were conducted in the communities

(e.g. in shelters - as some people were displaced and they were all sheltering at schools). The sessions were conducted, with women of all ages, and incontinence was included in those sessions. But soon the team realized that they also needed to reach men, and others who had incontinence – not only the women (although adding incontinence

into sessions like this for women, worked well).

Children's 'diapers' were distributed by the HP team

Mothers/ caregivers approached the HP volunteers, when their children had incontinence issues. They were referred to the local RC health clinic, to rule out any physical problem and then received a voucher, which they presented to the HP team and then received incontinence products (diapers). One challenge was the sizing of diapers, and how to manage this in an emergency response, where they had procured a large amount. (There was no local market on the islands, near the refugee camps to facilitate market based, or cash approaches). A more detailed case study is expected to be published in the near future.

They did some of the best HP in the Red Cross Movement in the Greece response. The team had a positive attitude and were open to work on new subjects they had not worked on before, as important issues. They had a very practical and common-sense approach and saw incontinence as a WASH issue, as well as understanding that it is also primarily a health issue, so both are needed. In both Greece and Honduras, the IFRC also supported health facilities in the camps, which also offers the opportunity for engagement across sectors.

See also the NCA case study – **CS-NCA-C** in **Supporting document 1**.

EXAMPLES - HUMANITARIAN RESPONSES ON INCONTINENCE – UKRAINE

 COUNTRY: UKRAINE 2016 - 2022

CASE STUDY: CS-GHA-B • CS-GHA-C

 DETAILS:

WASH CLUSTER LEADERSHIP AND FOR OLDER PEOPLE WITH INCONTINENCE



Mark Buttle, WASH Cluster Coordinator in Ukraine, during the Crimea response, 2016 to 2021

Mark Buttle was the WASH Cluster Coordinator in Ukraine from 2016 to 2021, during the conflict in eastern Ukraine, and he was also providing remote support in 2022.

Ukraine was one of the first large-scale humanitarian responses, where the WASH Cluster took proactive leadership on the incontinence issue, ensuring that the humanitarian response, at scale, responds to incontinence needs.

We asked Mark, to share how he came to become aware of this issue and to take it as his responsibility as the WASH Cluster Coordinator, to ensure that the humanitarian agencies responded. It is hoped that good practice, piloted in Ukraine, might inspire and encourage other WASH Clusters and coordination teams, to also take action on incontinence.

The full case study on how Mark, as the WASH Cluster Coordinator, and his team, got interested in this issue and took action, is very interesting and worth reading – see - **CS-GHA-B - Supporting document 1**.

The steps in Ukraine:

- **When Mark arrived in Ukraine in 2016**

HelpAge and HI were sharing and presenting new guidelines on people with disabilities in humanitarian action. In addition, large workshops for the development of the 2017 Humanitarian Response Plan for Ukraine, were underway. In those meetings, it was clear that the demographic of this emergency, included a large proportion of older people. Many stayed behind in the frontline villages, when the younger people and children left. These older people, had specific needs, including around the issue of incontinence.

- **Learning about needs of older people**

As time went on with the eastern Ukraine response, it started to become a forgotten crisis. The coordination team wanted to keep improving

standards of WASH work, but also wanted to showcase ways of working, that would bring global attention on the Ukraine response. The cluster team started working with HelpAge, to try and identify the main issues for older people, and set up a Hygiene Technical Working Group looking for solutions. The group identified a clear need to distribute bed pads and adult incontinence products (diapers), as well as the need to pilot the selective distribution of toilet chairs.

- **The Cluster Hygiene group, went through a process of learning over how to distribute incontinence-related items**

and also *Triangle Generation Humanitaire* (TGH), in partnership with UNICEF, started looking into the costs for possibly including extra items into the electronic, e-Voucher scheme, they were supporting. At this stage, the cluster realized the high cost of provision of incontinence-related items, both for older people and people with disabilities, as well as nappies for babies. The impact of such costs, on household budgets, was significant, and prohibitive to the use of the items by many, already conflict-affected, older, or disabled people.

- **Two new hygiene kits were developed**

One was for a “small family”, to provide additional hygiene items for an older couple, or for one disabled person and their carer, and then a complimentary “people with special needs” (PSN) kit, for supporting a person with specific incontinence problems. The PSN name was chosen, to try to avoid any stigma associated with asking for the kit. Items of the two kits can be found in the longer case study, **2 - Supporting document 1**. They include bed pads, incontinence pads (diapers), Zinc ointment, gloves and laundry soap and other items.

- **Initial briefing with WASH Cluster actors at the start of the 2022 response**

Another WASH sector actor, explained how Mark, as the WASH Cluster Coordinator, did an initial briefing for all WASH sector organisations, planning to work in Ukraine. During this briefing, he talked clearly about the need for WASH Cluster partner agencies, to support older people with their incontinence. This set the scene for what was expected of WASH sector actors, during the new, and hugely expanded response in Ukraine, since February 2022.

- **Hygiene promotion guidelines (2018) and kit lists**

These were already developed for the eastern Ukraine response and included requirements for incontinence, for this new response. They do not use the term incontinence, and do not specifically discuss leaking of urine or faeces, but they raise the issue that older people and people with disabilities and the need to add additional cash for their hygiene kits. The existing kit lists, were also shared.

- **Responding to incontinence issues was a learning process**

Not all issues were overcome, and some remain: for example, the use of creams, some of which are classified as pharmaceutical products – and are therefore difficult to distribute legally; the possible need for underwear distributions; the need for waterproof mattresses in hospitals; and challenges of disposing of solid and infectious waste.

The overall lessons to these efforts and results include:

- Widespread action supporting older people with their incontinence in Ukraine, has clearly been improved because of the WASH Cluster’s leadership on this issue. Being interested, committed and humble enough, to not just do what has always been done, and to start from first principles, to try and find solutions for the people most vulnerable in this response, has led to widespread action. This was focused on coordinating multiple agencies, to consider appropriate aid to the older target population, which included helping them with managing their incontinence.
- Recognizing the importance of working with HelpAge and HI, to identify possible solutions for older people, who are usually an overlooked group of people in humanitarian contexts, has also been very positive. By the WASH Cluster leadership standing up and talking about the responsibilities of all WASH sector actors to support older people with their incontinence, WASH sector organisations, were in the position that they cannot say ‘we didn’t know’, or ‘this is not a priority issue’, but knew they were expected to act.
- The Ukraine response, is unique in leadership coming from the WASH Cluster Coordination team on the incontinence issue, and is an excellent example of good practice. It is hoped that other WASH Cluster and other Cluster coordination teams will learn from Mark’s example. It would be great to see this case study, discussed in all global trainings for new WASH Cluster Coordinators.

CASE STUDY: CS-GHA-C

 DETAILS:

HUMANITARIAN AGENCY ACTIONS ACROSS CONTEXTS, ON INCONTINENCE IN UKRAINE

This case study shares experiences of a number of organisations, who have been involved in the recent, 2022, Ukraine response and have been involved in supporting people with incontinence.

Please note that prior to the 2022, organisations, which were particularly active in Ukraine, and have hence worked to support older people with their incontinence over a number of years, included: [WASH Cluster \(WC\)](#), [People in Need](#), [Caritas](#), [NRC](#), [UNICEF](#), [IOM](#), [ArcheNova](#), [Proliska](#), [VostokSOS](#), [ADRA](#)

This case study, however, focusses on a few examples of organisations, currently undertaking some activities related to incontinence in Ukraine. These are the organisations, who we had the opportunity, to interview representatives from. However, there are many other organisations working on the ground in Ukraine, some of whom may also be doing larger-scale and great work on this issue.

THIS CASE STUDY, INCLUDES SECTIONS ON:

| | | |
|---|---|--|
| <p>A Age and Disability Working Group – supported by HelpAge</p> | <p>B Norwegian Refugee Committee (NRC) – working across contexts</p> | <p>C Polish government – quickly installed support for people with disabilities</p> |
| <p>D Humanity and Inclusion – learning how to learn what is needed</p> | <p>E RedR – training for the WASH Cluster (2020)</p> | <p>F OXFAM – provision of NFIs, including from donations</p> |

Learning:

- **There is an Age and Disability working group in Ukraine**
HelpAge are supporting this and they have provided advice to the WASH Cluster.
- **Norwegian Refugee Committee (NRC)**
The work of NRC in Ukraine, is particularly interesting and useful, because the team worked to provide people with support on incontinence, in different contexts within the response. These included: a) elderly/care homes in the north; b) people trapped in the Donbass region in the East; c) hard to reach areas; and d) collective centres in the East and West of Ukraine. They adapted

their support for older people and people with disabilities, against the context, which will be very useful learning for development of subsequent responses. See – [CS-GHA-C - Supporting document 1](#) - for more details.

- **In Ukraine, HI started by working in institutions**
They asked themselves what support should we provide? The policy is often seen as distributing incontinence pads (diapers), but they had some concern over creating needs not there before. So, they decided to leave it up to the medical team to determine if incontinence support was

necessary and then to liaise with the WASH team. **In collective centres** – Here they did hygiene kit distribution, including a baby kit and incontinence kits for top-up and did quite a lot of thinking around how to distribute the items and how to decide when to provide the top-ups. See – **CS-GHA-E - Supporting document 1** - for more details.

- **The Government of Poland made a very positive effort, to support people with disabilities in the refugee response, through the 'Blue Dot' programme⁴⁵**

It allocated USD 17 million funding for this response. The Secretary of State for Disability, who himself has a disability, was responsible for the funding and programme. It included two key aspects. The first was provision of access to assistive devices and medical and hygiene support for people with disabilities and older people and people with chronic health conditions, who arrive in Poland if they needed them. People either needed to have their Ukrainian Disability Card / Certificate, or to sign a statement that you have one, even if it was left behind in Ukraine. They could then receive their prescription from a Pharmacy, with a code, so they don't need to pay for expenses. The second part, was that the government gave access to refugees to access social protection benefits and disability benefits, on level with Polish citizens. They had 1,700 applications and 400 have already been

processed. One of the biggest challenges is how to get the information to the people who are eligible, as they have no connection with the health system and may have no money. UNHCR were trying to share this information, through community-based structures. About 10% of the refugees have accessed the 'Blue Dot' scheme. There have also been some cash transfers through Health sector processes. See – **CS-GHA-C - Supporting document 1** - for more details.

- **RedR support for training in Ukraine**

RedR provided some training for the WASH Cluster on WASH project cycle management in 2020. This included a module looking at inclusion, and incontinence was part of this, as a topic that WASH actors are not often thinking about.

- **OXFAM – provision of NFIs including from donations**

The OXFAM team in Ukraine, acted without advocates trying to get this on the agenda by having to push, which was very positive. This was a testament to the WASH Cluster Coordinator's work in Ukraine. A lot of donations, were also seen in collective centres in Poland. These included pads and adult diapers, and bed pads. But there were still issues, especially at night-time, from adult and child incontinence, where volunteers would find the beds wet in the morning.

ALSO SEE THE FOLLOWING CASE STUDIES:

- **CS-GHA-B - Global WASH Cluster taking the lead on incontinence in Ukraine – Supporting document 1**
- **CS-NCA-G – HEKS-EPER – Ukraine – Non-WASH actors working on incontinence – Supporting document 1**

- Also see **Section 5.1.6** – for the use of the shopping trolleys in Ukraine by NRC, for older people to carry their NFIs

EXAMPLES - HUMANITARIAN RESPONSES ON INCONTINENCE – GBV AND FISTULA

 COUNTRY: KENYA 2007

 DETAILS:

NAIROBI WOMEN'S HOSPITAL – RESPONDING TO POST-ELECTION VIOLENCE

During the post-election violence in Kenya, the Nairobi Women's Hospital, supported multiple women and child-survivors of violence, throughout the country. Some women and men, had suffered other extreme violence and sexual assault⁴⁶, which also caused traumatic fistula, which also needed responding to⁴⁷.

We interviewed a former staff member, who worked at the Nairobi Women's Hospital during this period, who explained that the hospital through the GVRC (one stop centre) had to establish ways to manage the surging number of survivors reporting GBV at the hospital. The Hospital has a GVRC, that provides clinical management for survivors and case management, which included providing counselling and follow-up of the survivors. The former staff then used the learning through this role, to move on to work for a local NGO, by providing training on management of survivors' sexual assaults, to over 200 health providers, working in different levels of health care.

A Human-Rights Watch report, provided this case study (p10) on the incontinence-related impacts of the violence, due to GBV⁴⁸ see quotes:

'I am not at peace; my body is not the same. If I am pressed, urine just comes out. I feel weak. Sometimes I have a dirty-smelly discharge coming from my vagina. I feel pain in my lower abdomen. I have serious back ache.... I don't have money to go to a big hospital. I have so much shame. I feel hopeless. I just sit and wait to die.

I have problems sleeping. Sometimes I can go to bed at 10 p.m., be up at 11:30 p.m., and not fall sleep again. I doze off a lot during the day. I think about the rape, my financial problems, and the death of my husband [in the violence]. I was running a clothes boutique business in Nakuru and I had good money. But now I have become a beggar. Sometimes I don't have food. I don't have any help from my family.

I came here to my father-in-law's home after the violence and he gave me a plot of land to build. My brothers-in-law didn't want me. The land was registered in my brother-in-law's name and he wants the land back. I need help with land and a house for my children. I am just here in the village and I don't know how to reach the government to ask for help'.

 COUNTRY: SOMALIA, CAR & DRC

 DETAILS:

MSF INVOLVEMENT IN FISTULA CAMPAIGNS

A major activity of MSF, is the provision of basic and comprehensive obstetric care, and developing strategies to increase access of women to obstetric care. In many contexts where MSF works, access to care in general, and to women in particular, is a challenge. Uterine rupture and obstetric fistula (OF), typical outcomes of unattended obstructed labour, are the consequences of poor access to

emergency obstetric care. Where many women with Uterine rupture die unnoticed at home, others pay for their survival with an OF - the vast majority for the rest of their lives. Many of these women will be stigmatized and ostracized, because of the constant smell of urine or faeces, and left to live a miserable life outside their communities.

In some African contexts with a high OF prevalence (Somalia, CAR, DRC), OF campaigns have been organized around facilities where MSF was already running or supporting obstetric services. Field teams would identify and register OF patients and have them come back later, during the 4-6 weeks stay of a surgical team, trained to close OF.

Although a rewarding activity, OF care has not become a 'standard' type of intervention for MSF. Reasons: OF is not seen as a life-threatening condition and MSF prioritizes reducing directly life-threatening conditions and on increasing access to care (hence there are budgeting priorities here); challenges to maintain a pool of well-trained fistula surgeons; workload of already overburdened

teams – which has implications when organizing an OF campaign, which is (by definition) an 'add-on' to existing MSF emergency obstetric care programs.

See also:

- Case study: **CS-NCA-I – 2022 - Somalia – FGM and fistula – Supporting document 1**
- Case study: **CS-NCA-F – 2022 – DRC - Opportunities for WASH, GBV, ASRH engagement – Supporting document 1**
- Case study: **CS-GHA-G – Global – MSF – Integrating incontinence into health responses**

FISTULA CARE

CASE STUDY: CS-GHA-H

 DETAILS:

UNFPA & PARTNERS – FISTULA PREVENTION & RESPONSE

A detailed case study is in – **Supporting document 1** – covering the following subjects related to fistula care -

- UNFPA – and their work and approaches
- Obstetric, GBV-related fistula
- Campaign to End Fistula and UNFPA's role
- Identification of clients
- Fistula care
- Development of a community-based assessment tool for obstetric fistula
- Materials for managing fistula
- Examples, with countries with high caseloads of fistula
- Fistula and other post-partum incontinence related challenges
- Challenges with fistula surgery and fistula care
- Challenges for the global campaign
- Key actors in fistula care
- Fistula events
- Guidance

Key issues to be aware of for women with fistula

- Women with fistula are incontinent, but how and level varies for different people. The diagnosis is very variable, some have really drastic surgical procedures, which need medical support and radiographic inputs for the complications. There is a huge variety of fistula – from a huge hole to huge three- dimensional injury. The bigger damage comes from longer obstruction in delivery, where it takes a longer time to deliver.
- A proportion of women who have a successful fistula operation still have urinary incontinence, following the procedure. One study in Uganda found that despite successful closure of the fistula, 16% to 55% of women suffer from persistent urinary incontinence after surgery⁴⁹.
- There are also hidden connections to other forms of incontinence, leaving women very miserable, but they are often portrayed as a happy lady afterwards holding a baby. But it is not so infrequent that it works out this way. This is because as the baby works its way out,

there is a hole in the rectum and vagina and all the mechanics are destroyed at the same time – so they leak from urethra instead of fistula. So, some women leave wet, just as they were, before the operation. The real success rates have not been worked out.

- There is a difference between urine leakage, due to the bladder mechanism not functioning properly and obstetric fistula – where there is a hole in the bladder or urethra and permanent uncontrollable leakage.
- Sometimes we don't realize about the incontinence post-surgery, as a woman is catheterized for a couple of weeks after the surgery. Some women may also not know what they have, and they may have had issues before.
- It is also unknown, how many more women have died, because of uterus rupture on labour, as they may have died in their dwellings. A large proportion of women have incontinence post-partum, but for most it is temporary.
- There is also broader maternal morbidity which also occurs, such as prolapse of the uterus, as well as mental/psychosocial health problems.
- Also, where women and girls suffer from fistula, this is also seen as a taboo, with the victim smelling. There are also lots of stigma and beliefs around fistula and it can be seen as a punishment.
- People need to know how to talk about it and how to seek and find them in their homes.

- A community-based fistula screening tool has been developed by Habiba Mohamed, an experienced leader with the Fistula Foundation in Kenya and also creator and founder of the NGO, WADIDA⁵⁰.

Other key challenges

- There are challenges with the training of surgeons, many having inadequate training and skills and on-going support. Training is being undertaken, but more attention is needed, to support key doctors to gain a higher level of experience. Patient and safety of care must come first. Quality and not quantity of fistula surgeons' skills and surgeries is key.
- Hospitals often do not have enough funding for urodynamic testing, although there are simpler versions available.
- The focus is often more on the surgery, than the wider psychosocial support and support for livelihoods, that are also needed. One respondent described this, as the way fistula is handled, is a: *"Public health issue in a surgical sandwich"*.
- Fistula is seen as a rare condition, and it often not a priority, even in relation to sexual and reproductive health, even though it can occur during the process of maternal and neonatal mortality.

EXAMPLES - HUMANITARIAN RESPONSES ON INCONTINENCE – HEALTH AND DISABILITY RESPONSES

This table summarises case studies, on the work of HI and MSF, focussing on disability and health responses in humanitarian contexts. For more

details: **Supporting document 1 – CS-GHA-E and CS-GHA-G**

 COUNTRY: MULTIPLE COUNTRIES - ON-GOING

CASE STUDY: S-GHA-E

 DETAILS:

HI - SUPPORTING PEOPLE WITH SPINAL CORD INJURIES

This case study provides an overview of the learning that HI and its staff and partners have undertaken, while practically supporting people with incontinence over several decades. The experience, come from working a diverse range of contexts from, South East Asia, Syria / Turkey border, Haiti, Ukraine, Afghanistan, Burundi and elsewhere.

HI has also just developed their WASH strategy, which is focused on emergency/post-emergency contexts, which was validated last year. They acknowledged the value of HI being involved in the area of incontinence in rehabilitation colleges, and particularly in emergency situations. HI is working to structure their responses to incontinence more, as they continue to learn.

Lessons related to supporting people with spinal cord injuries -

- Incontinence management is a huge survival issue and challenges in managing incontinence still exist, when people go home from hospital.
- Some national authorities are balancing benefits and risks of catheterization as a practical solution. They may promote self-catheterization with reuse of catheters, knowing the hygiene and UTI risks, as this is more practical and sustainable than single use.
- HI developed specific protocols to support people with spinal cord injury, together with the International Continence Society and the

governments in Vietnam, Cambodia, Laos and Thailand. They have also developed material kits, mainly for catheterization and have established, an assistive list of products, which can be offered when needed. Through their use, they have also noted that people with mobility issues, more commonly need products provided for example: urinals, special toilet chairs. The toolkit items, can be seen through this link - <https://drive.google.com/drive/folders/1iN06isMpgl9vc6oDeARpHu-ugjrrGOH?usp=sharing>

COUNTRY LEARNING EXPERIENCES:

SYRIA

HI trialed the use of washable/reusable products and established linkages with existing specialist organisations, reducing the time to do so from, 2 years, to 6 months. For washable/reusable products, challenges were linked to availability on the local market, particularly related to catheters etc. For washable/reusable pads, more operational research was felt needed, as in some contexts, they can be difficult to clean and dry, particularly where WASH facilities and services are limited, or in colder periods.

HAITI

HI increased communication with people who have incontinence.

UKRAINE

HI has been working with institutions and establishing needs and trying to establish when they should provide top-up kits and through which mechanisms. HI undertook sensitization on what can be provided in terms of assistive items, so that people know if they need these items and they

can then ask for them. The learning process is ongoing in different contexts.

AFGHANISTAN

The HI team have been providing care at community level with people who are para and tetraplegic.

HI also has mobile teams in humanitarian contexts

They establish needs at household level, including for rehabilitation. During their visits they can ask about sanitation needs, but they do not have WASH specialists in the teams. The mobile teams focus on people with specific disabilities, such as people who are paraplegic. They can see the situation the person is in when they visit them at home, as they can smell if the person may have incontinence and is not managing it well and can go much deeper to check the needs. The mobile teams also have a psychosocial team member, who can do counselling, as well as a physiotherapist who can do the physical aspects.

Other learning

- People with disabilities, can also face sexual violence.
- It is important to work with caregivers and build their capacities.
- Continence still needs to be restored after surgery, using physio exercises.
- Women who had just given birth, were also accompanied to have a simple PAD test, where they are asked to drink 300 cc of water and do standard exercises. Then the pad is weighed before and after, to see the severity of the fistula. When it is over a certain value, they are given advice and asked to come back for other options, such as surgical procedures. A university in Belgium wrote an article on how to do this test and together with the two physio specialists from Belgium and Spain who helped to develop and test it.

HI WASH Strategy and staffing

- HI WASH strategy includes hygiene promotion and practical support to enable people to be able to maintain their hygiene. When they undertake hygiene kit distributions, they also check incontinence products are available in the

kits. HI is trying to provide a more personalized approach, as an alternative to supplying everyone with the same, to reach more people.

- HI is not a specialized agency in incontinence and they know that knowledge on this issue, is not standardized. Hence, there is a need to develop localized solutions in partnership with authorities and local agencies.
- There are gaps in availability of certain specialists in HI, available in required timelines in humanitarian responses, including WASH specialists. Teams tend to be of two main types: a) Specialist teams – who are well trained; and b) Other staff - called on an occasional basis, many of whom are not aware of good practices and protocols.
- People outside of the WASH sector, are also not always comfortable to talk about faeces, urine, shit etc., so sensitization and dialogue is needed.
- The needs for people who are mobile vs who are immobile, are likely to be different. Hence there is a need for specialized agencies, who can take over to support specific people, as HI are not a specialized agency on incontinence. There is no global solution for this issue, and a trade off in solutions.
- Need to provide patient education and sustainable solutions, and not just give incontinence pads (diapers) and go away. It is easier in a refugee camp to give diapers, but this can also take away self-reliance. So, there is some conflict over their provision. There is also some concern over de-skilling people and that no one size fits all. But in acute responses, there is a need to provide the basics for all who live with this condition, as well as offering different solutions, such a urine collector. In a camp setting, incontinence issues need to be responded to, before they become too big, and to help with physical rehabilitation.
- There is also a need to educate caregivers and to establish routines for food intake and use of the toilet, rather than just giving diapers. There is also a need for better awareness in the general public.
- We also need to adapt, with regional standards. Look at the products that are available in the local setting and the accepted protocols by local authorities.
- There is a need to consider both urinary and fecal incontinence.



CASE STUDY: CS-GHA-G



DETAILS:

MSF EXPERIENCES OF INTEGRATING INCONTINENCE INTO HEALTH RESPONSES

MSF is an international, medical humanitarian organisation working in more than 90 countries around the world, working in conflict zones, natural disasters and epidemics. It is hoped that this case study, will encourage more self-reflection from other health sector actors, in how the sector can better support people with incontinence through their work.

MSF works mainly with a medical lens and has some experience in stomas after war surgery and also some on fistula surgery, but otherwise have not had much engagement in this issue. Teams have however, seen a range of examples of people with incontinence through their work. For example, people with learning difficulties and older people. Patients with prostate and bladder cancer, are also often seen and there have also been cases of children wetting themselves, due to childhood trauma, when they are super scared. This might have resulted in bed wetting and they may have come to talk to the health service, to talk about the issue, to see if it was due to a medical reason. Elderly care is often invisible, except for occasional examples, such as an older gentleman who used to come in for intermittent catheterization support in Darfur.

Challenges/barriers for MSF organizationally

Support for people with incontinence, are not yet seen as part of the core commitments of medical doctors, and are not mentioned in documents. It is seen as a nurse's responsibility. There are also difficulties engaging across sectors, the same as in other organisations, including working across different health teams. Reflection is usually in siloes, so there is often a lack of multi-disciplinary work.

MSF uses a medical lens and often misses seeing the wider picture, so MSF often misses the "multidisciplinary team lens", where doctors, nurses, occupational specialists, or mental health

specialists, are one team. There is a need in shift of mindset from the medical focus, to a broader health focus. Another indication of this, is that it also took multiple years to get the incontinence items such as pads, nappies and incontinence sheets into the MSF catalogue. Previously, it was seen as not being an essential health or humanitarian item, but now MSF has some adult incontinence products in the catalogue.

Observations on practical needs and challenges in health-care settings

Key gaps on the practical needs and challenges in health care settings, include:

- There is limited access to incontinence nurse specialists, who can advise and provide care and capacity building for other staff on incontinence
- Mattresses and beds are not always waterproof, leading to embarrassment when someone soils the bed
- There is limited privacy in hospital settings, for people who are bed-bound in managing their toilet needs, including in cholera camps
- Sometimes there is overuse of invasive incontinence tools and products, such as an over catheterization of people, because of not having enough nursing staff, or not enough privacy to go to the toilet, or being unable to access the toilet (distance is too far, or there are not enough of them)
- There are challenges with language and how to talk about this issue, and we are not clear on the language to use and not confident on the words for the spectrum of leakage types and volumes
- People do not always feel comfortable to ask someone for help, even with significant challenges in their lives

- Males with incontinence may be more reticent to come forward
- Nurses may also be reticent to support patients and we often delegate toileting care to caregivers, as we don't have time as nurses. Plus there is also almost a stigma even in the health sector, to deal with incontinence
- Skin assessments need more priority, attention and assessment tools
- Moisture lesions are particularly difficult and pressure sores can be fatal, so there is a need for creams, but barrier cream is not yet in the MSF catalogue
- Mental health is often not prioritized, which forms a vicious cycle, but there can be huge issues with domestic abuse and violence in the family
- MSF is not an expert organisation in continence issues, or the pelvic floor exercises, with the physios focusing more on post traumatic injuries

EXAMPLES - HUMANITARIAN RESPONSES ON INCONTINENCE – VARIOUS

 COUNTRY: BANGLADESH 2018/19 • 2021

 DETAILS:

INFORMAL CROSS-SECTORAL WORKING GROUP ON MHM AND INCONTINENCE, 2018/19

In 2018, the informal MHM working group in the Rohingya response, agreed to change their name and focus to the 'MHM and incontinence working group'. The group was mainly working to try and encourage a great focus and coherence of support for women and girls, in managing their menstruation in the Rohingya humanitarian response. At the time, members included agencies, such as OXFAM, IFRC, WFP, UNICEF and a number of other agencies. A half day training session was run on incontinence and MHM for this group, during the Gender, GBV and Inclusion Audit of the work of the WASH sector in the Rohingya response in 2018/19. Participants

came across as interested in the incontinence issue, particularly, on whether making washable/ reusable incontinence products could become an income generating activity in the camps. This committee remained for the whole of 2019, but in 2022, it no longer exists. It is not clear, why it no longer exists, but it may have been that the people who were supporting it moved on from their positions, and no-one was prepared to take their place to support this group? The challenge of sustaining coordination structures, particularly when they are looking at newer areas of focus, is a problem with a high turnover of staff.

WASH AND INCONTINENCE SUPPORT IN THE ROHINGYA RESPONSE, 2018/19⁵¹

HelpAge had undertaken a study⁵² on the situation of 1,335 older people in the camps in 2018. They found that 17% openly admitted that they have incontinence problems and 77% of this group, stated that they were struggling and not getting any support. 43% of older people with disabilities, who have difficulty in getting out of their living place also reported having incontinence.

Only a very few responses, supporting people with disabilities with their WASH needs in the camps were identified at this stage, one year after over 750,000 refugees arrived, increasing the numbers of people in the response to 1.2 million. As far as was possible to establish at this stage, the WASH sector had only supported about 15 people with disabilities, out of hundreds of thousands of people

with disabilities and older people in the camps. The 15 people had been supported by a mixture of: NGO Forum/UNICEF, IFRC and OXFAM, as well as a few people supported by HI, CBM and HelpAge and their partners. Most support was given to improve the accessibility of toilets, but one NGO reported that it had also provided urine containers. HelpAge and its partner Resource Information Centre (RIC), and HI, CBM and DAC, had also provided urine containers and bed pans, to some older people and people with disabilities, and HelpAge/RIC also had provided some commode chairs for older people to use in their shelters. The NGO who had provided

urine containers, said that some problems had been faced with them, because children, had been using them as water/drinking containers. Also, RIC, shared that not all the toilet chairs provided were used, as some older people were not used to sitting, instead of squatting. So, the focus on making sure that people with disabilities and older people are able to meet their WASH needs effectively and with dignity at this stage of the response, one year after the major influx, was still not a priority. Awareness of the majority of WASH actors, working on this response at this time, was poor.

CROSS-SECTORAL DISCUSSION ON INCONTINENCE IN COX'S BAZAR, 2019

A cross-sectoral workshop was also run during the Gender, GBV and Inclusion Audit of the WASH sector in the Rohingya response in 2019. A presentation was made by Dr Fahmida Akter, a Fistula Surgeon at the Hope Foundation Hospital in Cox's Bazar. 77 of the fistula operations, which had been undertaken in the previous year in this hospital, had been undertaken on women from the Rohingya camps. The Hope Hospital, was working to train midwives and also works with fistula survivors to reach out to other women living with fistula, to encourage

them to also come and get the surgery undertaken. Many women are ostracized by their families due to this condition, and 92% of women who end up with fistula also lose their babies during the birth. So, it is a very traumatic condition.

The cross-sectoral discussion during this workshop, looked at the roles of Health, WASH and Gender and GBV actors, to try and identify the responsibilities of each sector, to support people living with this condition.

UNHCR SUPPORT TO PEOPLE WITH DISABILITIES IN THE ROHINGYA RESPONSE, 2021

The UNHCR 2021, Annual Report, documented the protection team's work with people with disabilities in Bangladesh. It does not specifically mention support for incontinence, but people received cash transfers, and a range of other support, which would be useful to someone with incontinence.

The Korean Agency for Development, seconded a person with disability experience to the response. There is also an older person and people with disabilities working group, and there has been some sanitation materials and psychosocial support provided. But data is aggregated, so not so easy to work out who is receiving support, such as widows, etc.

The report noted that UNHCR continued to implement a range of protection interventions related to mental health, psychosocial services, disability, gender equality, GBV prevention and response, child protection, and legal assistance. It noted that there are 1,579 site management volunteers, of whom

344 are female, one is transgender, and five have disabilities. It also noted that 100% of females of menstruation age, received sanitary materials, including females with disabilities.

Multi-purpose cash assistance was provided to targeted vulnerable individuals, such as older persons, persons with disabilities, and widows. In the last quarter of 2021, they received a one-time transfer in cash. It also noted that UNHCR focused on strengthening the protection environment for Rohingya refugees with specific needs (PSN), through cooperation with partners specializing in disability inclusion and ensuring they are mainstreamed in all community programmes. It also noted that home visits conducted. It noted that 47,444 PSNs were identified and assisted, of which 9,210 people's cases were considered urgent. It also noted that 6,976 refugees were accompanied to service points, referred 16,143 to specialized outreach volunteers and 4,386 cases to partners for assistance.

It reported that 2,842 group-based psychosocial support sessions were provided and a total of 2,192 persons with disabilities and older persons received physical and functional rehabilitation services. 207 people with disabilities and 2507 older people also received awareness raising, under community engagement activities during the March 2021 fires. 701 persons with disabilities and 3007 older persons also received awareness-raising on Covid-19, monsoon, fire prevention etc. Case

management, was also undertaken for 336 boys and 216 girls with disabilities and 442 children with disabilities, received psychosocial support.

It would also be positive and useful, if UNHCR could document if any WASH or incontinence-related assistance, is provided to the people with disabilities, which it has been supporting in the Rohingya response.

 COUNTRY: HONDURAS 2020 • 2021

AFTER HURRICANES ETA AND IOTA

CASE STUDY: CS-GHA-F

 DETAILS:

IFRC – WASH SUPPORT TO PARENTS AND CHILDREN WETTING THE BED DUE TO TRAUMA

In Honduras, the Spanish Red Cross Emergency Response Unit (ERU) were deployed. They had previously been trained on incontinence (together with MHM) and so there was an awareness and interest, to do something on incontinence.

They set up a hotline with a Red Cross Volunteer with a mobile phone. People with incontinence would call the hotline, and then Red Cross volunteers would deliver pads / incontinence materials to the household. Red Cross volunteers come from the same community, so this was a viable easy option (versus if a 'volunteer', or agency staff live in another area, and only visit every now and then).

They also undertook a study on whether they could use cash or vouchers. This was where they took vouchers to the tent, and then used them to get the products, including mattress protectors.

They also observed that women were used to bleeding, so as they were more used to using cloths, this made it more difficult to use what was provided. Sizing versus needs was also a challenge. They distributed 200 small and 600 medium sized incontinence pad packs. Initially the mistake was also made to consider that it was only women of all ages who had this need, which overlooked men.

 COUNTRY: ALGERIA 2021

 DETAILS:

UNHCR - INCONTINENCE AND PHYSIOTHERAPY SUPPORT TO PEOPLE WITH DISABILITIES

UNHCR provided physiotherapy services for persons with disabilities in Algeria. They continue to support them through the provision of physiotherapy materials, capacity building, training and payment of incentives, to 11 physiotherapists, to provide regular therapy sessions to identified (232) people. *Triangle*

Génération Humanitaire (TGH), also carried out 3 distributions of incontinence pads, to cover the needs of 792 out of 852 (93%) beneficiaries, including 587 older persons (94%) and 205 children with cerebral palsy (89%). A partner also provided 5 persons with crutches and wheelchairs.

 COUNTRY: HAITI

 DETAILS:

HUMANITY AND INCLUSION - SUPPORT TO PEOPLE WITH DISABILITIES

In Haiti, HI targeted people with disabilities, which included people living with incontinence, as they saw it was a huge gap for households, with people with disabilities and with older persons with disabilities.

They also realized, that when they distributed standards kits, these were not appropriate for

everyone, so they needed to be more specific in what they provided. The question was how could they do this? They proposed to resolve the issue through opening communication lines with people with incontinence issues and finding out their needs.

 COUNTRY: TUNISIA AND CAMEROON

 DETAILS:

It was reported that countries where increased efforts were made by the government, for people with disabilities in humanitarian responses, included Tunisia and Cameroon.

In a similar way to how the Government of Poland, provided financial support to people with

disabilities, efforts were also made in Tunisia and Cameroon as well, for them to get benefits the same as the population. The aim was to be inclusive of refugees.

5.2.2 Examples of global planned actions

A few examples are highlighted below, of actions which humanitarian actors have shared that they are planning to do over the coming months and years.

NCA

To roll out the recommendations of this mapping process, to strengthen integration and mainstreaming incontinence in WASH responses. To increase cross-sectoral engagement in incontinence and broaden their engagement in incontinence in humanitarian contexts in existing and new country contexts.

There will be others, but this provides a flavour of the kinds of activities planned by other actors:

Dr Amita Bhakta

Is hoping to continue to replicate the one-day training on the WASH needs of peri-menopausal women, previously run, in partnership with the RWSN. There is a plan to prepare a briefing note in 2023, with support of the Sanitation Learning Hub, on WASH needs of women going through the menopause process. This is expected to include part on their incontinence needs.

ELRHA/HIF research teams

A second stage of activities, post-completion of the first three researches on incontinence, which will be undertaken with collaboration between the research teams. This will focus on developing awareness-raising tools for WASH practitioners on incontinence.

IFRC

Are planning to release their WASH and incontinence guidance note in additional languages, and disseminate it throughout the Red Cross and Red Crescent Movement, globally.

IOM

The team in Ethiopia, is continuing with the support of NCA, to complete, their Innovation Norway-funded work, to innovate on incontinence products. This will include a market assessment, before decisions are made on the existing availability of products, or the need for new innovations and production.

Loving Humanity

Loving Humanity, would like to reach new users of the washable/reusable incontinence products, that they are already producing in their factory in Jordan, and disposable products in factories in Kenya, Iraq and soon in Sierra Leone. They hope to be able to reach and support more people affected by humanitarian emergencies.

LSHTM & ICDDR,B

A large-scale population-based survey being planned at the moment for Bangladesh, has included survey questions on urinary and faecal incontinence. For the LSHTM, the intention is also that, when possible, studies will continue to integrate incontinence into new research exploring WASH and disability

MSF

MSF are continuing to work across operational centres, to integrate more proactive efforts to focus on care and dignity of people living with incontinence in their programmes.

OXFAM

OXFAM has a few upcoming plans:

- They have started an evaluation of inclusion in their current country programmes, and will be including incontinence as part of this.
- They are also applying for some internal funds, to start piloting what people find useful to manage incontinence. The funding is not yet confirmed, but hopefully funds will be available.
- They are aiming to work towards the integration of incontinence as a normal part of OXFAM programming over the next few years.

- They are working on the next stage of the HIF/ELRHA funded-research, together with other partners, to develop awareness-raising materials on incontinence, with WASH sector actors.

Tampere University in Finland

The three MA students, who are just starting their MA thesis on humanitarian incontinence related subjects, FGM, sexual violence and violence against people with disabilities and incontinence in humanitarian spaces, will undertake their research and complete these in 2023.

UNHCR

The Protection Team, who also lead on disability and inclusion, have started a collaboration with the Health Unit. They have also employed a consultant, with a wide scope to look at assisted services and rehabilitation. This also considers where incontinence should sit and how they can share responsibility for this. It is looking in particular at Protection and Health collaboration.

UNICEF Supply & Innovation Division

The team will continue their research and learning into the development of the more comprehensive incontinence kit, for people with disabilities and other users. After it has been piloted on the ground, the next steps will be to finalise and send for tenders, to be able to add the kit into their emergency stocks.

WHO and UNICEF

They are currently rolling out the MOOC trainings on the recent items that have been added to the Assistive Products list, including absorbent products. In the next updates, they also hope to integrate catheters and associated equipment into the Assistive Product Lists.

World Vision, Vanuatu

Continuing to roll-out the work with people with disabilities to help them manage their incontinence. This includes the training of new artisans to make the wood pallet toilet chairs, in new islands across Vanuatu.

SECTION 6

OVERVIEW OF FINDINGS AND CONCLUSIONS



Bed pan in health facility, Nigeria
(Credit: S.House/Global Sanitation Fund/2016)

6.1

Progress and gaps in supporting people living with incontinence

This section brings together findings and conclusions from the efforts of NCA and wider global humanitarian actors, on supporting people living with incontinence in humanitarian contexts.

6.1.1

Global humanitarian leadership, cluster and cross-sectoral coordination



CURRENT PROGRESS

Increasing interest and engagement in incontinence - There has been some progress over the past 6 years, in raising awareness of the importance of the overlooked area of incontinence, in the humanitarian and LMIC development sectors and discussion across sectors. Initially, much of this has been through the actors engaged in the informal global email group on incontinence; and more latterly, through increased opportunities for learning through research and practical action on the ground and sharing of these findings, in some sectoral workshops.

WASH Cluster leadership on incontinence can make a difference - There has been one recent humanitarian response, Ukraine, where the WASH Cluster Coordinator, is known to have clearly raised the issue of responsibility of the WASH sector actors, to provide support to older people to manage their incontinence. This made a significant difference in terms of programming actions, and funding allocated to overcoming incontinence issues. Efforts have continued in the Ukraine response to keep incontinence on the agenda, to incorporate practical support for older people living with incontinence affected by this emergency.

Occasional discussions occurring in coordination mechanisms - Occasional discussions have occurred in WASH HP meetings, although usually only briefly. From 2018, to at least 2020, the informal MHM working group in the Rohingya humanitarian response, was known as the 'MHM and Incontinence WG' But this was not sustained over time. It is not clear what happened to this group after 2020. There have also been some discussions across sectors, such as on psychosocial support and health, but it has not tended to focus on practical solutions.



CURRENT GAPS AND BARRIERS

Limited commitment at cluster, sector, and organisational leadership levels - Globally, at country and response levels, across sectors and organisations.

Most cluster leadership across sectors, do not discuss responsibilities related to incontinence -

In most humanitarian responses, cluster leadership is not aware of the importance of incontinence and does not show leadership or highlight responsibility for actors to provide support in this area. This is felt to partly due to a lack of awareness of the problem, and also a reluctance, to adapt more tried and tested response modalities, people are more used to.

“At senior management level, this subject is not a top priority for anyone”

(Humanitarian sector actor)

Limited time and limited numbers of staff -

These result in issues such as incontinence, which are more complex, more hidden, and currently not stated, in the mandatory responsibilities of staff, tending to become overlooked. If the only WASH leadership in organisations, come from a technical background and are people who are used to focusing, mainly on water and toilets and other infrastructure, there is less likely to be a focus on broader issues, such as incontinence. Likewise, if humanitarian response, coordination teams are only made up of engineers and people who have worked on the water and sanitation side of WASH, without dedicated staff with hygiene promotion expertise, attention on incontinence is much less likely. This is unless the coordinators are exceptional in their commitment to ensuring the humanitarian responses are people-centered and meet the needs of different people with the communities.

Cross-sectoral nature of responsibilities poses challenges -

The fact that this is a cross-sectoral issue, with actions required across sectors, offers opportunities to benefit from people with a wide range of expertise, but it also poses challenges for coordination. It leads to questions over who takes leadership and responsibility for this subject. This issue needs to be understood and considered by every sector, in the same way, that GBV guidelines recommend for GBV, as this also cuts across the responsibilities of each sector.

Variations in the condition and wide range of people possibly affected by it poses challenges -

There are challenges from the complexity of the condition, such as the range of people potentially affected by it, types and levels of severity, as well as high level of embarrassment and stigma. This makes this subject more challenging than menstrual hygiene to manage and find solutions for.

Challenges from politics, competition between agencies and gaps in honesty within the humanitarian community, over challenges with programmes -

“There is still often the usual fighting between agencies, over who will be allocated which areas to work in and to get funding”, and in the early stages of emergencies, there tends to be a lot of competition between different NGOs. There are also challenges in terms of documentation of learning, because organisations are reticent to be honest about challenges / problems, concerned that they will then lose opportunities for funding. One respondent also highlighted, that with the provision of NFIs, it is also easier to ‘fudge’ reports and promote the image of success. Hence post-distribution monitoring is very important.

There has been a change in leadership and power in humanitarian organisations, which poses challenges for real accountability -

More than one respondent highlighted that today, the communications teams have become more powerful, which like to share positive stories, so problems tend to get hidden / not be so visible. In addition, *“Humanitarian agencies now tend to be*

“Which sector should coordinate? Each thinks the other should do this, such as WASH or GBV or ASRH”

(Humanitarian sector actor)

“Where did the common-sense go?”

(WASH humanitarian sector actor)

managed at senior management level by people with no experience in humanitarian responses. They come more from the private sector and they don't understand the realities on the ground. Having nice positive stories becomes their reality – it is visual accountability, rather than real accountability”.

There can also be challenges with competition between sectors - If there is a cash working group and a focus on multi-purpose cash i.e. for use to support the work of different sectors, there are some challenges from different sectors wanting to report on the expenditure. For example, the shelter sector, may want it reported under shelter, but WASH may want to report it under WASH, which adds competition.

Gaps in data on prevalence and a bias towards academic evidence, versus using common sense, listening to people and prioritising dignity - There is a lack of information on prevalence data, as this issue is generally hidden, and is difficult to establish.

6.1.2 General across all sectors

CURRENT PROGRESS

STANDARDS, GUIDANCE AND TOOLS

A significant step forward has been the inclusion of more specific guidance on incontinence in the Sphere standards - This has raised the profile of this overlooked issue and given a useful starting point for designing responses.

The global informal email group on incontinence has developed informal guidance on incontinence - This has provided a starting point for designing support and on-going learning on best practices, which will feed into updated guidance and standards going forward.

This is similar to the way the numbers for incidences of GBV, are also difficult to ascertain. So, it is difficult to know the full scale. This poses a challenge for planning and an even bigger barrier to gaining commitment to act. This is partly due to the over-focus on the importance of having exact numbers, fueled by the bias towards academic evidence. This is similar to the barriers which were faced for a number of years, which delayed action at scale on MHM. This was because there was too much emphasis on quantitative numbers of girls missing school, due to not being able to manage their periods, rather than using common sense and understanding the significant challenges to management related to embarrassment, dignity and rights. Luckily, in the area of MHM, many implementing agencies, continued their work, while the numbers argument, was being argued out by the academics and donor community. So, progress, was still being made on the ground. Whilst some ideas of numbers are needed, to ensure effective responses, for example, so as to know how many NFI products to support, or staff time to work on this issue; efforts need to be made to progress action and learning from the action, for incontinence as well, rather than getting stuck, on academic arguments over numbers.

The UNFPA ‘orange book’ has been updated for fistula surgery - This has updated global guidance on the latest best practices related to fistula surgery.

Protocols have been developed to support people living with spinal cord injury with self-catheterization - Humanity and Inclusion have been working over a number of years, in collaboration with governments in a number of countries and the International Continence Society, to develop protocols for supporting people living with spinal cord injury to undertake self-catheterization.

DONORS AND FUNDING

There has been some increased engagement of donors in the area of incontinence - Particular champions so far, have included the Norwegian Ministry of Foreign Affairs, who has funded NCA's work on incontinence. NCA developed an indicator on incontinence, which the NMFA approve and encouraged the planned work on incontinence.

They also funded some of the ELRHA's HIF managed research. Other donors of the HIF research include: the UK Foreign, Commonwealth and Development Office; Netherlands Ministry of Foreign Affairs; and ECHO. Other donors have funded practical support in programmes, via UN agencies, including UNHCR and UNICEF, and through a number of NGOs.

“Donors are increasing their demands, requiring all programmes to be inclusive, and so getting more technical partners for disability inclusion. But few are working to ensure inclusive WASH”

(Disability and WASH specialist)

INNOVATION AND SUPPLY

A number of efforts have been and are currently being made, related to innovation and supply related to incontinence solutions - This includes efforts by the UNICEF Supply Division Innovation team, working on innovations related to incontinence for people with disabilities; and also, the efforts that have been made to expand the GATE, WHO and UNICEF efforts, to update the list of Assistive Products. This includes more items related to incontinence, including absorptive products. The IOM, with funding from Innovation Norway and with support from NCA in Gambella, Ethiopia, are also investigating the needs for locally-produced re-usable baby nappies and adult incontinence pads.

Practical efforts have also been made to produce re-usable incontinence absorbent products - This includes in Vanuatu, by World Vision and Mama Laef, a private company, to develop re-usable incontinence pads, bed pads and cleaning mits/gloves; as well as making toilet chairs from waste wooden pallets. It also includes a number of washable/reusable incontinence items, being produced by Loving Humanity Charity, who has been producing disposable and washable/reusable baby nappies and incontinence pads and underwear. Their work started in Syrian refugee camps in Jordan, but now also expanded to other countries.

A range of smaller innovations are also in process or have also been made - This includes a pilot by NCA in South Sudan for the use of e-Vouchers cash transfer for more vulnerable households to gain additional support, which also considered people with incontinence. Plus, the use of shopping trolleys, to help older people more easily pick up and transport their NFIs, including incontinence NFIs. These were provided as part of the support from the NRC.

An open access practical, web-based continence advisory service is available, which has descriptions, specifications and feedback from product users - This has been established and supported by the University of Southampton and University College London, in the UK. It has been developed mainly on higher income experiences, but has relevance also for use by humanitarian actors and people working in LMICs. A third of the users of the site, come from LMICs. One of the most useful aspects of this site, is that it also includes feedback from the users of the products.

MONITORING, RESEARCH, LEARNING AND SHARING

A few significant positive steps have been made, in starting to learn about people's experiences of living with incontinence in humanitarian contexts

- This includes from a large-scale study in Vanuatu, undertaken by the LSHTM, World Vision and partners, looking at the MHM and incontinence experiences and needs, of people with disabilities compared to those of people without disabilities. Plus, also three researches were funded through the ELRHA/HIF programme, on the incontinence needs of older people, women with obstetric fistula and children.

There have also been a number of examples of learning from practical action on the ground

- For example, NCA has initiated this mapping process, to learn from their existing efforts on supporting people with incontinence across country programmes, and to identify barriers to action on a wider-scale. HI have been learning over a number of years, on the most effective

ways to support people with disabilities and in particular people with spinal cord injuries with their incontinence. MSF have been reflecting on their work in humanitarian contexts, and how it can be strengthened, in terms of ensuring dignity and care of their patients and has added absorbent products to their essential supply lists.

Increasing sharing of learning on incontinence

- The results of the Vanuatu research by LSHTM and World Vision, has been shared in a number of forums, as have the findings from the OXFAM/HelpAge-led research into older people living with incontinence in Malawi and Gambella, Ethiopia. The Global WASH Cluster HP Working Group, ran a webinar, as the first in their series on incontinence, which included an introduction, and updates from the three ELRHA/HIF-funded researches into older people, women with obstetric fistula and children.



CURRENT GAPS AND BARRIERS

STANDARDS, GUIDANCE AND TOOLS

More work is required on guidance related to incontinence for humanitarian contexts, for different actors, stages of emergencies and different contexts

- The general guidance pulled together by the global informal email group, was just an attempt to pull together information as a starting point, for consideration and action. This needs to be developed further, with inputs from the learning happening at programme level and feedback from people living with incontinence themselves. Guidance produced, needs to consider a range of actors, across sectors and be suitable for people who are working in face-to-face roles, as well as medical guidance for doctors, nurses, midwives, TBAs and other health staff. Plus, to guide responses during the first phase, such as in a rapid onset flood, versus what is possible in a protracted crisis and support suitable in displacement, natural disasters, or conflict situations.

Simple one-page checklists on responsibilities for each kind of actor, do not yet exist

- Simple guidance and visual tools for each kind of actor, would be very helpful, including those with simple images, which could be useful for actors engaging directly with communities.

Lack of knowledge on how to discuss this subject and fear of causing stigma, have been causing barriers for some actors to engage with people who live with this issue – This prevents engagement with people living with incontinence and their caregivers, excluding them from opportunities to have a voice, to share their experiences and in suggesting solutions. It will not be possible to find suitable solutions, unless people themselves are involved. People living with and managing this condition, are usually grateful for having the opportunity to discuss this issue and that people are interested. in the challenges they are facing in their lives.

INVOLVING PEOPLE LIVING WITH INCONTINENCE IN HUMANITARIAN CONTEXTS IN SOLUTIONS

A global disability specialist, stressed that, we assume it is understood, but in fact it's not fully understood by all.

“That a person who experiences the condition, should be at the front and centre of whatever you do – developing policies, strategies etc”

“It is a core human rights principle, it is something that has to happen, systemically and pro-actively”

Gaps in availability of assessment and monitoring tools - Although some work has been undertaken on developing different kinds of assessment tools and processes, as part of recent research, and some informal sharing has occurred, published assessment and monitoring tools are not yet widely available, for adaption by a wider set of actors.

FUNDING AND DONOR COMMITMENT

Challenges exist from decreasing budgets and multiple priorities - Decreasing budgets and multiple priorities, are posing challenges for prioritization of support for people who are more vulnerable, who have less voice and who have less champions, supporting their needs.

In the early stages of humanitarian responses, most equipment and NFIs are flown in to the affected area - This means that weight and space costs money, and so even items such as soaps, are often reduced from the requirements, to save costs.

Incontinence is still not a priority of most humanitarian donors and they are not clear enough on what they expect during calls for proposals - Most new actions, which happen at scale, happen because humanitarian responses, tend to be directed by what funding is available and hence, what the donors are asking for and requiring in terms of reporting (a clear example being the move to focus more on climate change

and resilience). For more challenging areas, like incontinence, which is a much more hidden issue, with people who are particularly vulnerable and have very little voice, there is a need for donors to be more specific about what they expect. This is particularly, because they are also under pressure to get a maximum number of beneficiaries per dollar; so, organisations are usually trying to focus more on activities, which give more beneficiaries for the same money, so their proposals will be funded. The more convincing donors are, about their commitment to supporting people who are more vulnerable and hidden, the more likely that implementation organisations will be willing to support them. Because not many donors have made this issue a priority, in most cases, there are no compulsory indicators for reporting actions on the ground. Action is therefore, still in general, limited by individual preferences and interest, except in the rare cases, such as Ukraine, where it has already been made a WASH Cluster sector priority.

“Donors also have a lack of a field presence, so this forms big problems with donors, where they hand over responsibility for morals, ethics and training and standards to the big agencies like UNICEF, IOM, UNHCR etc. But they in turn, just see partnerships, as contractors, to implement what they need to report on. This is mainly numbers of latrines or beneficiaries, with no-one really tracking morals / ethics and accountability”.

(WASH sector humanitarian actor)

INNOVATION AND SUPPLY

Learning in innovation/identification of existing products and supply and distribution mechanisms need to continue - The humanitarian sector still needs access to a menu of possible options for products and also mechanisms for distribution and feedback from users.

“There is a need for a change in donor mindset, in the donor’s approach”

(WASH sector humanitarian actor)

MONITORING, RESEARCH, LEARNING AND SHARING

In most emergencies, there are no targets or monitoring of actions related to incontinence - It is unusual for there to be targets for incontinence, which means no-one is systematically following

up, monitoring action and looking at the suitability of responses. Action has been based, more on personal feelings, drive and commitment, rather than systematic action.

6.1.3

Additional – WASH

CURRENT PROGRESS

The WASH Cluster coordination team in Ukraine, provided leadership on the importance of supporting people with incontinence - This is the first time that this has happened in a significant way in a humanitarian response, and so is a great opportunity to learn from. It is also understood that one WASH Sector Coordinator in Cox’s Bazar, in 2019/20, who had previously worked on the DCA/NCA programme, was also known to be committed to encouraging action on incontinence, but it is not clear if any specific actions occurred because of this.

A number of WASH organisations have already started trying to support people with incontinence in humanitarian contexts - Examples of practical support provided in humanitarian contexts, examples being in, but not limited to: Pakistan, Syria/Turkey, Iraq, Greece, Honduras, South Sudan and Ukraine.

A range of different approaches have been used to try and provide NFIs to people living with incontinence - This has included through the use of tables of hygiene items, for people on the move and hygiene kiosks, for people settled in camps, by IRC in Greece. And including a phone line by the IFRC for parents to call for additional support to help them manage their children’s bed-wetting, in Honduras. It has also included, the provision of NFIs to older people and people with disabilities in

care homes, as well as support in bomb shelters and collective centres, by the NRC in Ukraine. Plus, a range of organisations worked supporting older people, who remained in their homes on the frontline in the Crimea humanitarian response.

The WASH sector has improved needs identification processes, in some cases, and are more likely to ask people, what needs are and what are their preferences - This also opens up opportunities to better understand the needs and preferences for people living with incontinence.

The link made between MHM and hygiene kits, is a big step forward - This can be built on for incontinence.

Research on people’s experience of incontinence in humanitarian and LMIC contexts has focused on their WASH needs and priorities for support - This has included the research undertaken under funding by the ELRHA/HIF programme, focusing on older people, women with obstetric fistula and children; and also, the large-scale qualitative and quantitative research in Vanuatu with people with and without disabilities.

WASH sector actors have provided much of the driving force, to get incontinence talked about and on the humanitarian agenda - This has been supported by people across multiple sectors and professional backgrounds, making this an extraordinary area of collaboration, which will also be much needed, going forward.



CURRENT GAPS AND BARRIERS

Commitment is not yet widespread in the WASH Cluster coordination mechanisms at global and response levels - Until this happens, actions will not occur at scale, across WASH responses.

There is no one person responsible to make sure that incontinence is responded to in the WASH Cluster coordination mechanism, at response level - This risks, the subject being overlooked and relegated to, *“when we have time”*. There is a need to prioritize hygiene promotion and commit

“UNICEF has a massive responsibility as the WASH Cluster lead to ensure that WASH is inclusive. They need to discuss this with UNHCR as the camp managers, and with cluster partners. The cluster leads should have a strong voice – but they are currently wary of inclusive WASH. More has been done on the advocacy side related to disability”

(WASH and disability specialist)

“We also assume that consultation has to take a long time, but this is not necessarily true, as we can use simple questions and make rapid design changes”

(WASH sector humanitarian actor)

to a WASH Cluster level lead on HP, inclusion, MHM and incontinence, with dedicated time to lead and support on these issues.

Although there have been some improvements in recent years, focus still tends to be more on water supply, sanitation facilities (including faecal sludge management), with less attention on hygiene promotion and the needs of people from more vulnerable groups - All are needed, which means more attention is needed on hygiene promotion and the needs of people, who are more vulnerable and hidden.

The sector is still in the early stages of learning on how to identify, distribute NFIs and also provide other support to people with incontinence and their caregivers - A good start is being made, but much more practice and documentation and sharing of experiences and learning is needed – covering both positive and challenges.

The WASH community tends to use a standard approach and format and assume that consultation takes too long - when this is not true.

There is often a high turnover of staff and many staff without prior humanitarian, or WASH experience, working in WASH and community mobilization roles - So there is a lot for many people working in the WASH sector, and particularly people engaging directly with community members, to learn. This means that handling the more sensitive issues, is an additional challenge, including how to undertake this communication sensitively.

The WASH sector is often highly biased towards male actors and in some countries, it is difficult for female staff to work in the field - This poses challenges to reaching women and girls and talking about more sensitive issues.

“Considering the needs of the most vulnerable groups is still not yet a priority of the WASH sector”

(WASH sector humanitarian actor)

6.1.4

Additional – Protection and GBV



CURRENT PROGRESS

A large-scale distribution of incontinence absorbent products occurred the Syria response by the protection team in UNHCR in 2021 - It is understood, that many of the people supported with these products, were children and teenagers who had started wetting the bed due to trauma, although other people, including people with disabilities, were also supported.

Protection actors have also been involved with WASH actors, in other responses working to support caregivers of parents of children wetting the bed - For example, in the humanitarian responses by the IFRC and national societies in both Greece and Honduras.

The protection and GBV sector actors, together with health sector actors, have been providing some support to females and males, affected by serious GBV and rape, resulting in fistula - For example, the NCA GBV team has been supporting the training of health staff in a fistula hospital in Bukavu, DRC, to understand good practices in relation to working with people who are survivors of GBV. UNFPA, the Fistula Foundation, MSF and HI and others actors have been working on this issue, as noted in other sections of this report.



CURRENT GAPS AND BARRIERS

Currently there is a gap in awareness-raising, on how to prevent violence against people living with incontinence, by their caregivers - This needs significant attention, to identify the challenges, establish ways to reduce this risk, and to train other actors across sectors (including health, WASH etc), to know what they should be doing within their own spheres of influence, to reduce these risks.

Referral pathways need to be clarified for a person living with incontinence, particularly if abuse is suspected - If interviewing someone, there is a need to know about protection risks for the person living with the condition, and know the referral pathways for situations when caregiver abuse is suspected.

A big challenge will be how to support people discretely, who have started being incontinent, or have fistula due to rape, or other forms of violence - This is because, the person will need to also communicate with their family, over the management of their incontinence, particularly if it is severe, but may not want to disclose the serious sexual assault they have faced. Challenges are also faced, by women/adolescent girls who suffer from obstetric fistula, which is covered in other sections of this report, as living with fistula is also stigmatizing for these women/girls. They also need support to manage their incontinence, as well as the physical, mental, emotional and socio-cultural/ socio- economic consequences of this disability.

Particular advice is needed on how to encourage males, who have faced sexual violence or sexual torture, to come forward for support on incontinence or fistula - There are additional barriers for men and boys, to admit having faced sexual violence or torture, so additional guidance will be needed on how to reach and support men and boys living with incontinence, including in particular, because of such traumatic experiences.

There is still a need to integrate questions on incontinence and needs, into GBV screening and assessment processes - People may not openly share about incontinence-related challenges they are facing, even if they are severe, due to shame or stigma over this issue. So, pro-active sensitive questioning, will hopefully encourage them to share more openly. Examples exist of screening tools, which can be built on. This includes a community-based fistula screening tool, which has been developed by Habiba Mohamed, an experienced leader with the Fistula Foundation in Kenya, and also creator and founder of the NGO, WADADIA^{53, 54}

There is currently no, or very limited, involvement of older people or people with disabilities in the safe spaces - There is rarely anyone beyond 65 years and also rarely people with disabilities, who come to the safe spaces. There are also no activities designed for them in safe spaces. They tend to mainly be seen at household level, unless an older person's organisation, or disability organisation, provides any alternative services.

Cash is popular, but there may still probably protection risks from cash - There is not enough known about this and how to prevent protection risks from the provision of cash, so this should also be considered, if cash is also provided for incontinence-related products.

6.1.5

Additional - ASRH/SRH and fistula care

CURRENT PROGRESS

SRH:

SRH work on promoting safe births, contributes to a reduction in risk for obstetric fistula - But, it is not clear how much awareness-raising is undertaken on this risk is provided for mothers, due to give birth, including child, adolescent and young mothers.

Some SRH actors support safe spaces, which also have a medical officer and MHPSS specialist present - It is not known, whether any of the SRH safe spaces have already discussed issues such as incontinence, but SRH specialists would be well placed to be able to discuss incontinence sensitivity. This is as they already handle safe abortion care and modern family planning methods, which are often culturally sensitive.

There is some controversy around the potential links between FGM and fistula, but recent analysis of published studies, has indicated that fistula risk is increased in women who have had Type III or Type IV FGM, but not type I or II⁵⁵ - Some support is being provided through fistula hospitals and fistula campaigns, to encourage women to have surgery – For example, both MSF and NCA, have provided some support, whether practical or financial to support fistula surgeries in Somalia.

FISTULA:

A number of fistula hospitals exist, and are being used by women affected by fistula from humanitarian contexts and in other contexts temporary fistula campaigns are intermittently

established - They are providing fistula surgery and some provide other support, such as for livelihoods and reintegration.



CURRENT GAPS AND BARRIERS

SRH:

The SRH sector, has not yet pro-actively integrated incontinence and its prevention and response into its work, apart from its efforts to encourage safe births - There should be multiple opportunities, to integrate this issue into the existing work of the SRH sector.

There is concern over including this subject under the SRH area of responsibility - This is because SRH actors are concerned to take on this issue, when already their other issues, such as prevention of maternal mortality, neonatal care and safe abortions, are life-saving, but already under-funded and already do not get enough attention.

Sometimes understanding on incontinence is **FISTULA:**

Challenges are faced with some fistula surgery, where the surgeons undertaking the operations are not sufficiently skilled, to undertake the operations - This leaves women with continued problems and leakage to manage going forward.

Not all fistula services, also provide guidance on how to manage any residual leakage, or a way to be reintegrated into their communities and families - This has been identified clearly in the HIF funded research in Ghana, on WASH needs of women who have obstetric fistula.

limited, either considering it only affects women giving birth, or is only due to fistula - Whereas in reality there are multiple kinds and different reasons, for a lack of bladder or feecal control.

There is an Inter-Agency Working Group on Reproductive Health in Crises with a website and chat options and an IWAG SRH Interagency Field Manual⁵⁶ - This interagency field manual does mention fistula briefly due to sexual violence (pp 61, 190 and 200) and fistula due to obstetric complications, particularly for adolescents (pp 61, 114, 180, 201), although the information is a understood to be a bit outdated. However, it does not mention or address any other form of incontinence specifically (a search of the word 'incontinence', led to no finds in the 270 pages).

Adolescents are often an overlooked group in relation to SRH - But they are at higher risk of child marriage and higher risk of traumatic birth and maternal mortality, hence leaving them at higher risk of fistula and other forms of incontinence.

"If a woman is referred for fistula surgery, she may need to wait for a year, but no guidance is given as to how to manage the leakage in the interim"

(Health sector humanitarian actor)

6.1.6

Additional – Health, nursing, midwifery, physiotherapy and OT services



CURRENT PROGRESS

Health actors, are already providing some services for people living with incontinence -

This will vary by service, but this might be limited to referral to a fistula hospital for women with obstetric fistula. Incontinence may also only be identified, when a patient comes to the service on another issue. They are also providing care for women and girls during the birthing process. Health actors are also providing some services to people living with incontinence, through the provision of stoma bags, in response to conflict-related trauma injuries, and are seeing patients with incontinence resulting from cancer of the prostate, or bladder. In addition, some support has been given to parents and children, where the children or teenagers have started wetting the bed, due to their traumatic experiences, during war or displacement.



CURRENT GAPS AND BARRIERS

There is often an imbalance between a focus on the medical vs health approach -

This leads to an imbalance between the focus on care and dignity and wider impacts, such as mental health-related, or secondary impacts (the health approach) vs only medical solutions (such as surgery, or provision of drugs), with care and dignity being overlooked.

Even healthcare providers, including doctors, may not have knowledge on this subject -

This subject may not be included in the medical training of health care providers, including doctors, so their confidence in dealing with the different kinds of incontinence, may also be lacking.

In some countries, there may be some specialized rehabilitation centres for people with spinal cord injuries -

But they may be centralized and not easily accessible across the country. Some medical and general colleges, may also have neuro or orthopedic surgeons and physiotherapists, but in many places, they may not exist.

Basic advice, which is offered to all women giving birth in some higher income countries, such as advice on doing pelvic floor exercises from a physiotherapist, is often not available in lower income contexts -

This can leave a woman or girl with a residual incontinence after birth, which potentially they could have resolved.

6.1.7

Additional – Mental health and psychosocial support



CURRENT PROGRESS

Some examples exist of MHPSS teams getting involved in incontinence-related issues - For example, it is reported that MSF provided support from their MHPSS team in Iraq, to provide training for parents, trying to support their children who had started wetting the bed due to traumatic experiences of conflict.

St John of God Hospitaller Services (SJOG), in Malawi, who provide mental health support for half of Malawi, were involved in the ELRHA/HIF-funded research, on older people living with incontinence in Malawi - A mental health expert from SJOG, joined the research team in Malawi, for the OXFAM/HelpAge-led research, to advise the team and support learning from, and in relation to older people with incontinence, who also have dementia, and their caregivers.



CURRENT GAPS AND BARRIERS

Living with incontinence leads to psychological problems, which might cause anxiety or depression and prevent people from leaving their shelter to ask for assistance - This is currently an under-recognized and overlooked area for support.

A number of examples have been shared where people living with incontinence have had suicidal thoughts - Again, this is an under-recognized problem, for which support is currently not given.

People living with incontinence, may face abuse and violence from their caregivers, or be denied food or drink, to reduce the incidences of incontinence - All sector actors need guidance on how to reduce these risks, how to spot problems that are occurring, and what do to in terms of referral, if this is the case.

6.1.8

Additional - Older persons and disability actors



CURRENT PROGRESS

Some of the most sustained engagement in incontinence support, has been by disability sector actors - For example, HI have been working for years, to improve the support they provide to people with spinal cord injuries, including guidance on self-catheterization. CBM have also undertaken work, together with World Vision in Sri Lanka, to develop simple practical guidance on providing practical support to people with additional hygiene needs, including for incontinence.

HI has developed an internal set of protocols, to guide their support on incontinence - This includes specifications for assistive aids and NFIs, including a long-handled mirror for checking for bed sores, and cleaning equipment, as well as more commonly known options, such as commode chairs, urine containers, catheters, catheter bags, stoma bags and other associated equipment.

Disability specialist mobile teams, sometimes provide tailored-support to people living with incontinence and their caregivers - In HI supported programmes, the mobile teams usually include an occupational therapist or a physiotherapist, and hence they are more able to effectively assess the person's situation and needs.

Older person organisations are also increasingly engaging in this issue - HelpAge is known to have provided advice and support to the WASH Cluster in the Ukraine, Crimea response. This also contributed to identification of NFIs, to support older people with incontinence, being included in the hygiene promotion guidelines for the Cluster. HelpAge and their partner the Malawi Network of Older person's Organisations (MANEPO) also worked on the OXFAM-led ELRHA/HIF research related to older people living with incontinence in humanitarian contexts.

Age and disability working groups, exist in some emergencies - An age and disability working group, has been operational in the Rohingya response and in Ukraine. These offer an opportunity, to develop strategies to support older people and people living with incontinence in humanitarian contexts.

Some efforts to ensure that people with disabilities have access to toilets has been undertaken in humanitarian responses - An example has been included in **Section 5.2.1** -

from work undertaken by OXFAM in the Pakistan earthquake response, in 2005/6. But such actions still tend to be limited, or small-scale.



CURRENT GAPS AND BARRIERS

People with disabilities and older people and their needs, are still often overlooked in humanitarian contexts - People with disabilities and older people, are often overlooked or only considered in the later stages of humanitarian responses, after people who face less challenges have been supported. In this sense, they are still often being treated like second-class citizens, as their specific needs are not being looked into or assessed.

Older people living alone, or as an older person couple, may face particular challenges in managing their incontinence - They may find it particularly difficult to collect adequate volumes of water, to reach a communal toilet and also to manage laundry and cleaning soiled clothes. They may also have less access to resources and be less able to earn a living, and hence less able to purchase soap and other items.

Older people with dementia and their caregivers often face even more challenges in managing their incontinence - They currently are unlikely to receive adequate support.

6.1.9

Additional - Education and child-friendly spaces



CURRENT PROGRESS

UNICEF through their education supply division, has been supporting the innovation of products to support people with disabilities to be able to manage their incontinence, including in the school environment - This has included add-ons to traditional emergency toilet slabs to make the toilets more accessible, and also more recently incontinence-related hygiene kits. Large numbers have been sent to the Ukraine response, although feedback has not yet been received on their use.

“Inclusive WASH is in its early stages of consideration in emergencies. More people internally are aware and if we consider it from the beginning, the additional work is not as big as you think. But we don't consider it from the start, people argue against it due to limited budget and risks to life being the top priority. But it is easier if do inclusive WASH if from the beginning, than do it afterwards”.

(Disability & WASH global actor)

Some schools in LMICs, have accessible school toilets, although numbers are still low - But there is some increased awareness on the need for accessible facilities.

One of the HIF supported researches, has focused on children with incontinence in humanitarian contexts - This research has been led by Leeds University / University of Western Australia, with a number of partners and research in Uganda and Bangladesh. A comic book FGD tool based on the Story Book methodology, has been developed to ask children their opinions, on what they imagine it would be like living with incontinence, based on the experience of an imaginary character. This offers a tool and opportunity, to start discussing incontinence with children, and to discuss it in general terms in the school and CFS settings.



CURRENT GAPS AND BARRIERS

There is still a need to hear and document the views of children living with incontinence and their caregivers and their priorities for support - A number of humanitarian actors have already been engaging on a daily basis, with parents of

children living with incontinence in humanitarian contexts, and particularly, in relation to children who have started wetting the bed, due to having faced traumatic situations, such as due to experiencing conflict. The implementing agencies, should be encouraged to themselves, document the learning they are having through this daily engagement with the parents of children who are wetting the bed in humanitarian contexts and the children themselves. In addition, in particular to document, the ways that the parents and children, would like the humanitarian response agencies, to improve their efforts to support them. As Protection, MHPSS, Health and WASH teams, have already had key roles in engaging with parents and children facing these challenges in humanitarian responses, a collaboration between these actors, is likely to produce useful lessons and recommendations, which will improve the way that others will work in the future.

It is expected that most children living with more severe forms of incontinence, are not participating in schools or CFS - This is posing a barrier to their learning, and social and life opportunities.

6.1.10

Additional – Camp management, shelter, logistics and supply



CURRENT PROGRESS

The Shelter Chapter of Sphere, 2018, has mentioned incontinence twice - The Shelter Chapter, links to the NFI-related guidance, included in the hygiene promotion section in the WASH Chapter of Sphere.

Work has been undertaken by WHO and UNICEF, related to assistive aids, including absorbent products and also establishing hygiene kits for people with disabilities / special needs kits - The Absorbent Products TAP training is online, large number of these hygiene kits have been sent to Ukraine, and innovation and learning is on-going, led by UNICEF Supply Division.

Loving Humanity in Jordan and other locations and World Vision with Mama Laef in Vanuatu, have been developing re-usable incontinence products and tools - The Loving Humanity products, have already been used in a number of humanitarian contexts and there are opportunities for wider distribution of the Loving Humanity products. In Vanuatu, a pilot has been undertaken to support older people living with incontinence.



CURRENT GAPS AND BARRIERS

It is not known, if pro-active actions have been undertaken, to identify or support people with incontinence by camp management or shelter actors in community responses - It is assumed that this is a gap, but more work will be required to identify if examples of good practices exist, which can be learnt from. And also, to identify where standard procedures can be improved, to support people with incontinence. This could include, whether simple questions could be added during registration processes, associated with camp management.

Learning is progressing, but is still in early stages, to compare preferences and use of washable/reusable products for incontinence and the associated items, which should be included in NFI-related kits - There are likely to be positive and negative aspects of both washable/ reusable and disposable options, as well as other associated supporting items – absorbent products, catheters and associated equipment, mattress protectors etc.

SECTION 7

RECOMMENDATIONS

Photo: Håvard Bjelland / NCA



7.1

Top ten overview recommendations

The following are the top ten overview recommendations, for the global humanitarian sector to strengthen support for people with incontinence in humanitarian contexts.

- 1.** Constantly reflect on what we are aiming for in humanitarian responses – ensuring life, health and dignity - and emphasize that we will not be able to ensure any of these, without supporting people living with incontinence
- 2.** Increase awareness and commitment at global IASC and Cluster Coordination levels, on the cross-sectoral responsibilities, to support people living with incontinence in humanitarian contexts.
- 3.** Identify the routes for engagement in incontinence across sectors, through integration in and building on, existing activities.
- 4.** Ensure that in every humanitarian response, each cluster coordination team knows its responsibilities for advocating, supporting and monitoring their sector's actions in this area.
- 5.** Donors and UN agencies to specify requirements for humanitarian responses they fund, to include support for people living with incontinence.
- 6.** Develop basic standards, guidelines and tools, for use in each sector, considering the needs of different professions and actors, including staff working directly with communities.
- 7.** Develop and run capacity building, focused on the training needs of different sector actors.
- 8.** Increase opportunities to learn from people who live with incontinence and their caregivers, to involve them in developing and testing solutions for support in humanitarian contexts.
- 9.** Raise awareness on what incontinence is, who lives with it, the challenges and the solutions, with all humanitarian actors globally and within responses.
- 10.** Learn about the mental health impacts of living with and caring for someone with incontinence and practical steps that can be taken to reduce risks to violence towards people living with incontinence.

7.2

Recommendations for NCA

The following recommendations are being made for the NCA for the next steps in moving forward.

NCA-R1 – INTEGRATE INCONTINENCE SUPPORT IN ALL WASH, GBV AND ASRH HUMANITARIAN RESPONSES

Make commitments structural - Senior NCA leadership and management commitment will be needed to enable incontinence to be fully integrated into the work of NCA. It should be a compulsory component of NCA's humanitarian response, and should be supported across sectors. It must be a

structural requirement and should not just rely on committed individuals to support it, based on their own interests. The efforts to implement these recommendations, should start before the launch of the strategic exercise for planning the new NORAD and NMFA agreements.

NCA-R2 - BUILD AWARENESS AND COMMITMENT OF NCA SENIOR MANAGEMENT

Undertake advocacy upwards with the senior management – This should include, the Secretary General, the Heads of Department, and specifically including the Department for Communication and Politics, to help them understand:

- How well this issue aligns with the values of NCA, particularly related to its duty protect, to ensuring human dignity and particularly for people who are more vulnerable or excluded; including supporting social justice, working towards inclusive communities and integrating compassion in its work.
- How fundamental supporting people living with incontinence is, to enabling them to live with dignity and that it our responsibility to restore the dignity of people we assist.
- That by supporting people with incontinence, this will also be contributing to the prevention of GBV, as incontinence, can lead to abuse by caregivers and harassment in the community.
- Providing support on incontinence, also supports the improvement of mental and psychosocial health.
- How the NCA is uniquely placed to provide leadership on this issue globally across sectors, because of its work on WASH, GBV and ASRH in

humanitarian contexts and how it was the NCAs work, which started off the global dialogue and collaboration on this issue.

- How it can be a pioneer in the Global WASH sector, as there are not so many organisations which have a strong voice on this issue, and in particular in relation to implementation in humanitarian contexts.
- That supporting people with incontinence, is already very much part of the programme framework and developing this work forward, builds on the current work of the NCA.
- That this is a subject that the Ministry of Foreign Affairs will greatly value and that there would also be more funding opportunities.
- That it should be a strong component in the new NMFA Agreement next year and to emphasize the importance of how it needs to be working across sectors, in a holistic way and to be comprehensive.
- That there is a need to focus on and provide commitment and funding for cross-cutting issues, such as incontinence and working with people with disabilities. These areas tend to be neglected.

NCA-R3 - STRENGTHEN COORDINATION, PLANNING, BASELINES AND PROGRAMMES

Strengthen the linkages for working between WASH, GBV and ASRH teams - Through establishing practical mechanisms, as to how to engage on this issue, and developing collaborative plans on how to work to support country programmes across sectors. To start through building on existing interest and engagement in countries, where particular interest has already been shown, for cross-sectoral working.

To strengthen log-frames, planning and establishing baselines - There is a need to be more systematic, with providing support on incontinence, being a compulsory indicator for WASH. There is a need to establish the baseline in each country programme and the priorities for action in each country programme.

Develop a country programme perspective, in each country context - This needs to provide tangible guidance on what should be done, practically step-by-step. This should consider the different contexts where people may be supported in the country context, and to provide guidance for the implementation roll-out and distribution of NFIs.

Establish on-going learning and sharing - This needs to be both internally and externally.

Consider staffing - To consider if in each humanitarian response, can one staff or partner member, be employed for responsibility for HP, MHM and incontinence?

NCA-R4 – STRENGTHEN BUDGETS AND REPORTING AND INCREASE FUNDING FOR INCONTINENCE

Increase fund-raising efforts to support incontinence activities - for building capacity and in programmes.

Encourage applications for the next round of innovation funding, to use it for incontinence - For example, to encourage the DRC team to apply, as they are working in a fistula hospital already and have interest and commitment to try and work in this area, across sectors.

Make incontinence clearer in budgets
Include specific requirements for reporting on efforts to work on incontinence

NCA-R5 - DEVELOP TOOLS, GUIDANCE AND TRAINING (NCA SPECIFIC OR SUPPORT GLOBAL DEVELOPMENT)

Establish entry points - NCA needs to consider what are the entry points for incontinence services? For example, where people are referred to meet other needs, where they could then be referred for incontinence services. So, to consider which other services do people tend to encounter first? How can the programmes also engage with caregivers most effectively?

Establish responses by phases and different sectoral actors - First phase, protracted and cyclic situations. NCA has different teams for development and humanitarian contexts. There is a need to clarify the roles that each sector will have, and which activities and logistical support will be provided.

Establish how to talk about incontinence - How to make people feel comfortable and be respectful, and how to talk with different groups of people, children, males and females who have experienced sexual assault, older people etc.

To develop a toolkit of tools and materials, that will form a standard package - The incontinence toolkit of tools, should be integrated into the existing Emergency GBV and WASH toolkits, to form standard package. This can then be used, for new staff arriving in NCA, which should be the minimum standard package for the NCA programmes. Within this, it should also identify the minimum standards for NCA, including the top priorities for

action. It should include materials needed, which will vary depending on each kind of user. There is also a need for such tools, for both NCA and the wider humanitarian community, so NCA will need to decide, how much time and resources are put into their own organisational tools, and how much into global humanitarian tools. Both are needed, but considering that it usually, takes a longer timeline, to encourage collaborative action across agencies and sectors, work may still be needed on NCA-specific tools initially. This is while at the same time, also working to encourage cross-agency and cross-sectoral collaboration, for jointly published tools.

Assessment and monitoring tools - There is a need to integrate incontinence into all existing WASH,

GBV and ASRH assessment and monitoring tools. There is also a need to include guidance on how to talk about this issue, how to assess the needs, how to assess what is on the market and how to use the items, and how to monitor progress. Need to know what questions should be included in each sectoral assessment and monitoring process.

Develop and / or conduct / ensure training for different staff and partners - For WASH, GBV, ASRH, health/medical actors, for team members working at different levels, including health staff and staff and partners working directly with communities.

NCA-R6 – CONTINUE TO LEAD BY DOING AND UNDERTAKE CROSS-SECTORAL ADVOCACY

Develop awareness-raising and advocacy tools - These are for use for raising awareness across NCA and externally. For this, there will be a need to develop tools to start the conversation with different actors. This should start, before the launch of the strategic exercise for NORAD & NMFA. One opportunity will be to continue to build on the MHM advocacy campaign in Norway.

Continue to lead by doing - Leading by doing, and integrating incontinence into NCA humanitarian responses, will continue to give NCA credibility, when working through advocacy, to influence others. It will also assist NCA, to be able to share practical learning from its own experiences.

Work with other partners, to undertake advocacy at Cluster level - This is to convince cluster actors across sectors, to get engaged at global and country levels

7.3

Recommendations for global humanitarian actors (GHA)

7.3.1

Global humanitarian leadership, cluster and cross-sectoral coordination

GHA-R1 - INCREASE AWARENESS AND COMMITMENT AT GLOBAL IASC AND CLUSTER COORDINATION LEVELS, ON THE CROSS-SECTORAL RESPONSIBILITIES TO SUPPORT PEOPLE LIVING WITH INCONTINENCE IN HUMANITARIAN CONTEXTS

- Identify entry points for engagement in incontinence across sectors, through integration in, and building on existing activities and building new linkages and mechanisms for connection between them.
- Ensure that in all humanitarian responses, national cluster or sector coordination teams understand incontinence-related programming options, and know their responsibilities for advocating, supporting and monitoring their sector's actions around incontinence.
- Make sure that that a specific cluster coordination team member is responsible, for making sure this support is given to the affected populations, and has dedicated time to work on this responsibility.
- Emphasize that support for people living with incontinence, is a priority and not an optional activity. Supporting people with incontinence, should be mandatory for all agencies engaging in the key sectors.
- Incontinence needs to be integrated into the Annual Humanitarian Programme Cycle, through Humanitarian Needs Overviews, and Annual Humanitarian Response Plan, to ensure commitment, monitoring and reporting of the incontinence issue, and to open up funding for appropriate programming from Country Based Pooled Fund (CBPF) mechanisms.

GHA-R2 – GLOBAL WASH CLUSTER / UNICEF, TO COORDINATE AND DOCUMENT LEARNING TO SUPPORTING PEOPLE WITH INCONTINENCE IN THE UKRAINE RESPONSE

Make the most of the unique situation of the Ukraine response, to document learning on supporting people with incontinence. The Global WASH Cluster / UNICEF, as the lead for the WASH Cluster globally, should take the lead on this learning.

WASH CLUSTER COORDINATION LEADERSHIP ON INCONTINENCE OFFERS UNIQUE OPPORTUNITY FOR LEARNING

Ukraine is the first global humanitarian emergency, where Cluster Coordination has pro-actively included supporting people with incontinence in a Cluster's work. This has led to multiple agencies, some for the first time, working on how to support older people with their incontinence. This offers a critically important opportunity for the WASH Cluster and the humanitarian community to learn on how to effectively support people on this issue.

7.3.2

General recommendations for all sectors

GHA-R3 – DONORS TO SPECIFY REQUIREMENTS FOR SUPPORTING PEOPLE WITH THEIR INCONTINENCE

Funding, planning, monitoring and reporting

- Donors and UN agencies to specify requirements for humanitarian responses they fund, to include support for people living with incontinence.
- Increase funding to be allocated to support for people living with incontinence.
- Support for incontinence needs be planned, and to be continued over time, not just one-off support.
- Inclusion in programmes, needs to be stated in proposal development. Proposals usually cover a 2 to 3-year period, so work needs to be done on this now, to ensure funding will be available for the next few years.

“The push from donors needs to not just be in WASH, but also health – there needs to be a push from donors to be inclusive”

(Disability and WASH Specialist)

GHA-R4 – DEVELOP STANDARDS, ASSESSMENT AND OTHER TOOLS SUITABLE FOR DIFFERENT USERS

Standards, guidelines, assessment and other tools

- Develop basic standards, guidelines and tools, for use in each sector, considering the needs of different professions and actors.
- Develop one-page to two-page summary, on what each actor at each level, needs to know about incontinence, including at coordination and management levels.
- Prepare an information leaflet, with general information on incontinence, who lives with it, what are often the basic needs and recommendations on how to be polite and encouraging people to speak and not be silent.
- In particular consider the backgrounds and experience of staff working directly with

communities and where appropriate, use simple formats for basic minimum topics for discussion and options for support, for example with images of NFI products and assistance options available.

Assessment tools

- Develop assessment questions to add into existing rapid and more detailed assessment tools, which look into the needs of people who are living with incontinence.
- Consider building on the Washington Group questions for humanitarian contexts, to incorporate questions related to incontinence.
- Also, see below, for more requirements related to monitoring, evaluation and learning.

GHA-R5 - BUILD CAPACITIES OF ACTORS ACROSS ROLES TO UNDERSTAND RESPONSIBILITIES RELATED TO INCONTINENCE

Capacity building

- Raise awareness on what incontinence is, who lives with it, the challenges and the solutions, with all humanitarian actors globally and within responses. Also see the box below.
- Partner with organisations of people with disabilities (OPDs) and informal groups of people with disabilities, including women-specific groups, to raise their awareness on incontinence, and to also build other sectors' knowledge of the humanitarian needs of people with disabilities.
- Develop and run capacity building, focused on the training needs of different sector actors.

CORE SUBJECTS TO BE INCLUDED IN GUIDANCE AND TRAINING

- What is incontinence, severity, types and who lives with it?
- Identify good practices in discussing this topic, in a way that is polite, sensitive and dignified, and allows people to speak for themselves, recognizing they are the experts on living with their own condition, with practical challenges they are going through daily.
- What are the typical needs of people with different kinds of incontinence?
- What are the options for support?
- Which professionals and which sectors should be involved and their responsibilities?
- Assessment questions for adaptation.
- Facilitation approaches, to break the silence on this issue, in community and group settings.
- Identify useful approaches for also discussing incontinence with men, male and female adolescents and children and their caregivers.
- Guidance for working with caregivers, to reduce scolding and violence towards adults or children with incontinence.

GHA-R6 – LEARN FROM PEOPLE WHO LIVE WITH INCONTINENCE IN HUMANITARIAN CONTEXTS, AS TO THEIR NEEDS

Learning from people who live with incontinence and their caregivers

- Increase opportunities to learn from people who live with incontinence and their caregivers, to involve them in developing and testing solutions for support in humanitarian contexts.
- Document experiences of working on incontinence – both what works and does

not work – success stories and challenges, specifically including feedback from people being supported.

- Undertake post-distribution monitoring for distributions of items for incontinence, including on the processes for distribution, and the suitability of the items.

7.3.3 Additional - WASH

In addition to the general recommendations above in **Sections 7.3.1 and 7.3.2:**

GHA-R7 – IN THE WASH SECTOR, INTEGRATE INCONTINENCE INTO THEIR STANDARD PROGRAMMES, TO IMPROVE ACCESS TO WASH FACILITIES, RAISE AWARENESS, CLARIFY NFI NEEDS AND DEVELOP DISTRIBUTION OPTIONS

ACCESSIBLE TOILETS AND BATHING FACILITIES:

- Ensure all WASH facilities have basic features, which make them more accessible for the general population to use, such as adequate space, including handrails or ropes, or simple seats for resting, hooks and shelves.
- Separate, or screen WASH infrastructure (particularly toilets, bathing and laundry facilities; and in some situations, also water points), by gender and reduce queues to access facilities. Making WASH facilities more suitable for both females and males to use with privacy, can mean that women and men with incontinence, will be happier to use them, and hence making it easier to manage their incontinence.
- Include some fully accessible toilets and bathing facilities, for people with more severe disabilities and to allow them to access facilities.
- Provide options of toilet chairs, urine containers, bed pans, additional buckets with lids, mirrors with handles, and other practical items

RAISING AWARENESS:

- Ensure / increase female staff (ideally 50%), to be able to have these conversations with females as well as males.
- Contribute also to awareness-creation, through undertaking practical actions, such as constructing accessible latrines for people with disabilities and discrete disposal options.

NFI KITS:

- Establish and prepare guidance and lists and specifications of hygiene kits for people living with incontinence, on the WASH Cluster website – globally and on the WASH Cluster websites, for each humanitarian context
- Consider appropriate names for additional kits, which minimize stigma for people requesting them.
- Consider what kind of dignity kits and content, would be culturally acceptable in diverse communities.

- Consider different needs and different sizes and absorbencies of items, such as absorbent materials and suitability for adults and children (consultation is very important, as well as post-distribution monitoring – see the general recommendations above).

OPTIONS FOR DISTRIBUTIONS, SEEKING SUPPORT AND NFIS:

- Consider mechanisms for a one-stop-shop channel for people to be able to request and

receive assistance for incontinence, as well as other hygiene items.

- Consider the kinds of distributions which will be appropriate in each context – for example, whether in the early stages, or inaccessible locations, such as bomb shelters during conflicts, if blanket distributions would be more suitable, becoming more targeted, as soon as is feasible.

7.3.4 Additional – Protection & GBV

In addition to the general recommendations above in **Sections 7.3.1 and 7.3.2:**

GHA-R8 – RAISE AWARENESS ON THE MENTAL HEALTH IMPACTS OF LIVING WITH AND CARING FOR SOMEONE WITH INCONTINENCE AND APPROACHES TO REDUCE RISKS OF VIOLENCE TOWARDS PEOPLE WHO LIVE WITH THIS CONDITION

- Work together with MHPSS teams, to develop approaches and guidance for working with caregivers, to reduce scolding, and other forms of abuse or violence, towards adults or children with incontinence.

- Provide mental health support, to people living with incontinence and their caregivers.
- Support other teams (WASH, Health, ASRH, shelter, logistics etc), on how to be supportive of people living with incontinence and their caregivers.

7.3.5 Additional – ASRH/SRH and fistula care

In addition to the general recommendations above in **Sections 7.3.1 and 7.3.2:**

GHA-R9 – UTILIZE EXISTING OPPORTUNITIES WITHIN THE WORK OF SRH PROFESSIONALS, TO REACH PEOPLE WHO USE THEIR SERVICES, WITH INFORMATION ON INCONTINENCE AND WHERE TO GO TO GET SUPPORT

- Utilize the opportunities of having women together in safe spaces, and the confidentially involved in the safe spaces, to raise awareness on incontinence and how to prevent, minimize or manage it, when going through child-birth, or at any stage of the life-course.
- Raise awareness on incontinence, of the people the sector works with, including on its links to FGM (particularly Types III and IV). Include specific information for pregnant adolescents

about the risk of incontinence and how to reduce the risks and manage it, if it occurs.

- Work with TBAs to educate them on supporting women and girls with fistula and other forms of incontinence.
- Provide advice/ counselling on prevention of incontinence and fistula.
- Raise awareness of SRH staff, on the risk of urinary tract infections due to fistula, with

women who may come through SRH clinics, as well as the treatment options.

- Establish an internal referral system amongst sectors, to ensure continuation of support between sectors, and also at a larger-scale, amongst different organisations / service providers.
- Link with WASH teams for additional NFIs (including hygiene kits, incontinence pads, where suitable washable/washable/reusable, bed protectors, extra soap, and / or cash support to cover these items, etc) and improve access to toilets and bathing facilities, or to GBV, MHPSS or other services as needed.
- Provider referrals to healthcare or a fistula hospital.

GHA-R10 – STRENGTHEN COLLABORATION ACROSS SECTORS, TO PREVENT FISTULA AND STRENGTHEN CARE AND SERVICES, TO SUPPORT FISTULA SURVIVORS TO MANAGE THEIR INCONTINENCE MORE EFFECTIVELY AND LEAD TO HEALTHY, PRODUCTIVE AND DIGNIFIED LIVES

FISTULA SERVICES:

- Promote and enhance skilled health personnel, providing care during childbirth to ensure access to safe births.
- Increase awareness at community level about the services available and how to access fistula services.
- Encourage health services in each country to follow the good practices, in the updated global guidance by UNFPA and the Campaign to End Fistula, entitled – *Guiding principles for clinical management and program development – Obstetric Fistula and other Forms of Female Genital Fistula*⁵⁷.
- Establish protocols, options and materials, for assisting females and males with fistula, to be able to manage their urinary or fecal incontinence, before attending and after leaving the hospital for fistula surgery, also recognizing that not all operations will resolve the person's incontinence fully.
- Ensure that people with fistula, receive mental health / psychosocial support, to manage the situation they are facing and reactions from their families and communities.
- Focus on supporting women, girls, men and boys who have had obstetric fistula, or fistula after a sexual assault / GBV, to develop livelihood options, and to assist with their re-integration back into their communities.
- Strengthen the linkages between the fistula services and other support services, such as psychosocial support and protection services, especially for survivors of sexual assault.
- Explore more the different kinds of strategies will assist to re-integrate women and girls after surgery and increase efforts to help women and girls re-integrate into their families and communities after surgery.

7.3.6

Additional – Health, nursing, midwifery, physiotherapy and OT services

In addition to the general recommendations above in **Sections 7.3.1 and 7.3.2:**

GHA-R11 – STRENGTHEN THE MULTI-DISCIPLINARY TEAM APPROACH, AND CARE AND DIGNITY WITHIN HEALTH SERVICES, BUILDING CAPACITY OF ALL STAFF, FROM DOCTORS TO SUPPORT STAFF AND IMPROVE FACILITIES AND PROCEDURES TO SUPPORT PEOPLE WITH INCONTINENCE

HEALTH PROFESSIONALS:

- Consistent advocacy is needed for the provision of continence products, and strengthening the work force – including on the medical management of continence.
- WHO to develop basic global training, specifically for doctors and associated personnel, from the medical perspective, on the management of incontinence, as this subject may not be in their standard medical training.
- Focus more using a public health and health approach, instead of a 'medical' approach, to ensure that people are supported with all of their needs, including to help them retain their dignity when accessing health services.
- Establish the existing expertise in health services and options for referral, or linkages for utilizing existing expertise in training humanitarian actors (for example, staff from the Ministry of Health, who already provide support to people for catheterization, staff from disability rehabilitation centres, existing fistula hospitals etc.).
- Clarify which kinds of incontinence are treatable and which are not, and the ways to manage the kinds which are not treatable.
- Clarify how and when to use temporary catheters – such as after surgeries and for people with spinal injuries - and on appropriate procedures on self-catheterization, where government health authorities approve this system of management.
- Establish systems for follow-up of patients who have incontinence, to check how they are managing and if any additional support might be needed.

COMMUNITY HEALTH ENGAGEMENT:

- Work specifically with Community Health Workers (CHW), especially to increase their awareness about incontinence, the potential risks, related strategies to provide education, support referrals, identify people with incontinence and help them to access to the health services. The CHW could also support the

distribution of pampers, hygiene kits, etc.

- Be pragmatic, when developing guidance and tools for staff working at community level, as they may have limited levels of formal education, so they just need to know the basics, including to know how to acknowledge a person's experiences, if living with incontinence.

HEALTH FACILITIES:

- Health facilities should have incontinence pads of different sizes, or hygiene kits with essential hygiene supplies for people with incontinence
- Develop questions to integrate into existing nursing screening tools, for people accessing health services. This means including questions on experience of, and psychological issues related to management of a person's incontinence, when asking questions to patients on arrival at the health facility.
- Management to make sure that in-and out patients who are living with incontinence, have dignified ways to manage their incontinence, while queuing, waiting for appointments, admitted to hospital wards, or in other services associated with the health facility.
- Make sure that mattresses are either waterproof, which are checked regularly for cracks, or can be covered with mattress protectors / bed pads, which are changed regularly.
- Train all staff, including reception and cleaning staff to being polite and respectful and good practices in supporting people visiting the health facilities living with incontinence, including how to react if they have a bad smell due to urine or faeces or soiled clothes.
- Ensure toilets and bathing facilities are suitable for older people and people with disabilities, and water and discrete disposal systems are in place for absorbent products and a discrete waste management collection and end disposal system is established.
- Set up follow-up procedures for people with incontinence, especially after childbirth, or sexual assault, to monitor status, healing, or to identify potential complications.

GHA-R12 – STRENGTHEN CAPACITY AND OPERATIONAL PROCEDURES, RELATED TO MIDWIFERY, PHYSIOTHERAPY AND OCCUPATIONAL HEALTH SERVICES, TO STRENGTHEN INTERVENTIONS RELATED TO PREVENTION, CARE AND REHABILITATION OF PEOPLE LIVING WITH INCONTINENCE

MIDWIFERY SERVICES:

- Train midwives, nurses and TBAs, to understand preventative measures to prevent incontinence on childbirth.
- Provide patients with advice on options for managing any incontinence which has occurred during child-birth, or after a sexual assault.
- Midwives and TBAs to be trained how to refer patients to a doctor or fistula service, where a woman is leaking urine after childbirth.
- Ensure that midwives and TBAs can access supplies to support incontinence for women and girls who experience incontinence after childbirth or sexual assault.

PHYSIOTHERAPY AND OCCUPATION THERAPY (OT) SERVICES:

- Develop culturally appropriate guidance for

undertaking pelvic floor exercises, which community, midwives, traditional birth attendants, health and hygiene workers, can integrate into their activities with communities.

- Establish protocols for supporting women and adolescent girls who have just given birth, on how to strengthen their pelvic floors and ensure this is undertaken before women are discharged from health care facilities, after having given birth.
- Provide patients with advice on options for managing incontinence, which was not suitable for treatment, or not fully resolved.
- Establish assessment protocols for visiting shelters and other accommodation, to assess accessibility needs to be able to manage incontinence with dignity.
- Develop guidance and a checklist on how to identify if shelters meet the needs of people with incontinence

7.3.7

Additional – Mental health and psychosocial support

In addition to the general recommendations above in **Sections 7.3.1 and 7.3.2:**

GHA-R13 – DEVELOP APPROACHES FOR SUPPORTING PEOPLE LIVING WITH INCONTINENCE AND THEIR CAREGIVERS, WITH THEIR MENTAL HEALTH AND TO REDUCE RISKS OF ABUSE AND VIOLENCE TOWARDS PEOPLE LIVING WITH IT

- Develop approaches for providing support to people living with incontinence to support their mental health.
- Provide mental health support to people living with incontinence and their caregivers.
- Build capacity of other teams, on how to be supportive of people living with incontinence

and their caregivers.

- Protection and GBV specialists, to develop approaches and guidance for working with caregivers to reduce scolding and violence towards adults, or children with incontinence.
- Establish mechanisms and guidance on processes for referral for other sector actors, who have concerns about risks of abuse and violence.

7.3.8

Additional - Older persons and disability actors

In addition to the general recommendations above in **Sections 7.3.1 and 7.3.2:**

GHA-R14 – STRENGTHEN UNDERSTANDING, CAPACITIES AND PRACTICAL SUPPORT FOR OLDER PEOPLE AND PEOPLE WITH DISABILITIES (INCLUDING FISTULA SURVIVORS) IN MANAGING THEIR INCONTINENCE

- Provide information on support available / link with WASH, health, MHPSS teams.
- Collaborate with other actors to organise home-based care and support, such as for collection of water.
- Monitor access to support, through regular follow-up.
- Provide physio support and assistive aids for mobility and for incontinence management.
- Work with health sector professionals, to provide specific support for people with spinal cord injuries, including on catheter use and maintenance.

7.3.9

Additional - Education and child-friendly spaces

In addition to the general recommendations above in **Sections 7.3.1 and 7.3.2:**

GHA-R15 – BUILD CAPACITY OF SCHOOL AND CFS STAFF AND ENSURE EFFECTIVE ACCESS TO WASH SERVICES FOR CHILDREN AND STAFF LIVING WITH INCONTINENCE, WHO USE, OR WORK IN THEIR SERVICES

- Ensure easy access to accessible, age appropriate, gender-segregated toilets and hand-washing facilities for staff and children, which have discrete disposal options for absorbent products.
- Ensure access to soap and absorbent products for children known to have this condition.
- Teach staff, including teaching assistants, how to engage with children who live with incontinence and their caregivers, including asking them questions on what support they need and how they can help in the school or health facility environment
- Teach staff, including teaching assistants, how to help children to go to the toilet and how to support any children using catheters and urinary bags, or absorbent products, on how to manage them.
- Establish ways to raise awareness in children and their families, of incontinence, its challenges, possible solutions, and where they can go to get support.
- Link families with health, disability and WASH teams as appropriate, for support to be provided to people living with incontinence and their carers at household levels.

7.3.10

Additional – Camp management, shelter, logistics and supply

In addition to the general recommendations above in **Sections 7.3.1 and 7.3.2:**

GHA-R16 – BUILD CAPACITY OF CAMP MANAGEMENT, SHELTER, LOGISTICS AND SUPPLY STAFF TO UNDERSTAND THEIR ROLES RELATED TO SUPPORTING PEOPLE WITH INCONTINENCE

- Establish opportunities for engaging with actors, working actors on camp management, shelter, logistics and supply, to continue to build awareness and encourage discussion on this issue, to establish responsibilities and actions which should be integrated into operating procedures.
- Identify simple questions, which could be added into camp registration processes, which could provisionally identify people who live with this condition, for individual follow-up for further discussions on needs for support.
- Continue the work that the UNICEF Supply Division have started, to innovate, test and procure for emergency NFI kits for people living with incontinence for front-end emergency use.

ANNEXES

I • CONTRIBUTORS

II • NCA KNOWLEDGE AND EXPERIENCE SURVEY

III • GUIDANCE, RESEARCH, CAPACITY BUILDING

IV • ENDNOTES



Annex I

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WORLD VISION

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A number of other professionals also responded to emails, to either link the team with other colleagues or confirming that as far as they are aware, their organisation has not been involved in incontinence to-date.

Annex II

NCA knowledge and experience survey

An online survey was run for NCA staff across WASH, GBV and ASRH sectors and also open for other colleagues if interested. Some questions were compulsory and others were optional, so that participants could chose to respond anonymously

if they preferred. After the introductory webinar had been completed, the participants were given one week to complete the survey.

PURPOSE OF THE ONLINE SURVEY

1. *The purpose of this online survey, was to help the NCA understand the level of knowledge, confidence and interest of NCA staff in the area of engaging with and supporting people living with incontinence in humanitarian contexts.*
2. *It aimed to understand actions taken so far, as well as the barriers and challenges and ideas for how it can strengthen the work of the NCA in this regard.*

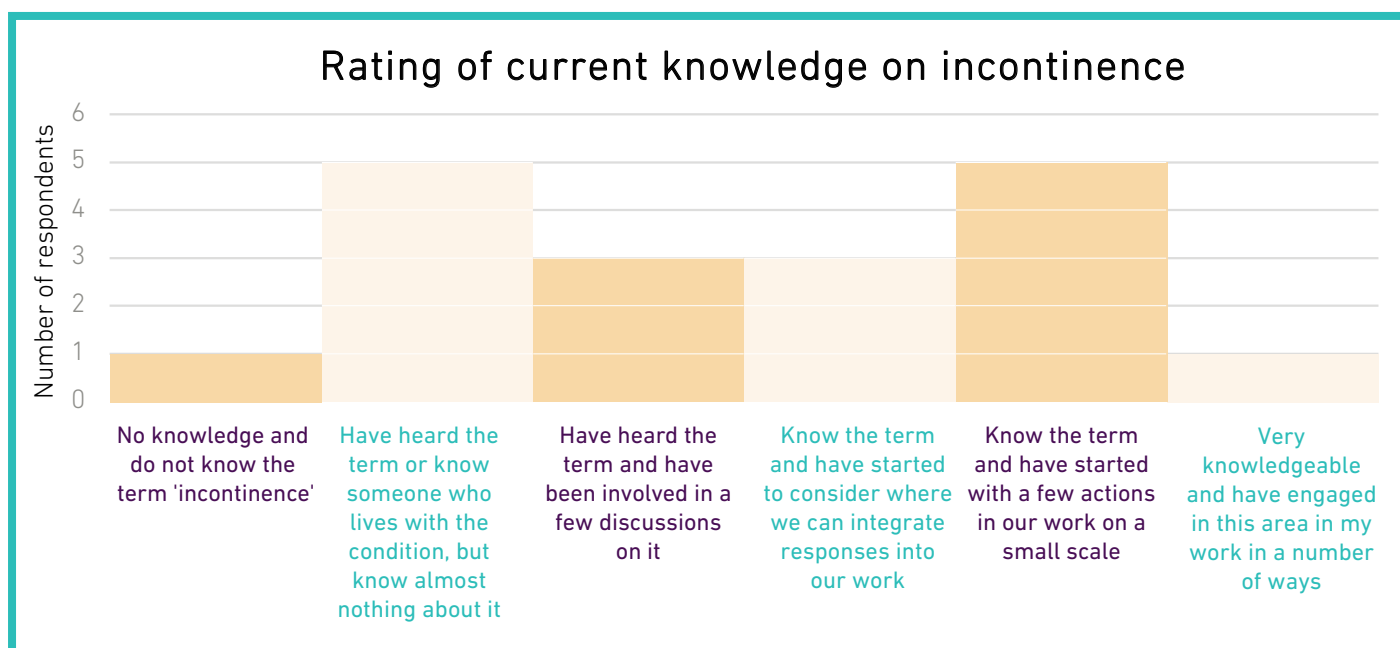
PARTICIPANTS IN THE NCA ONLINE SURVEY

18 people (13m/ 5f) participated in the online survey, 22% were in 18-30; and 78% in 31-50 age-bracket. Of the participants 67% work in WASH; and 17% in GBV and 17% in ASRH (some may work in both but the respondents were only given the option to indicate one or the other). Participants are working in the following regions of the world – 61% Africa;

17% Asia; 6% Middle East; 11% HO; and one stated as other. Participants who shared their country location (question was optional) – were working in Mali, Afghanistan, Bangladesh, DRC, Ethiopia, Mali/ Burkina Faso, Somalia and Syria/Lebanon and the HO.

ONLINE SURVEY RESPONSES

QUESTION 1 - PLEASE RATE YOUR CURRENT KNOWLEDGE ON WORKING WITH AND SUPPORTING PEOPLE WITH INCONTINENCE?



In response to the question to rate your current knowledge on incontinence, there was a reasonably wide range of responses, with half being on the less and half on the more confident in their

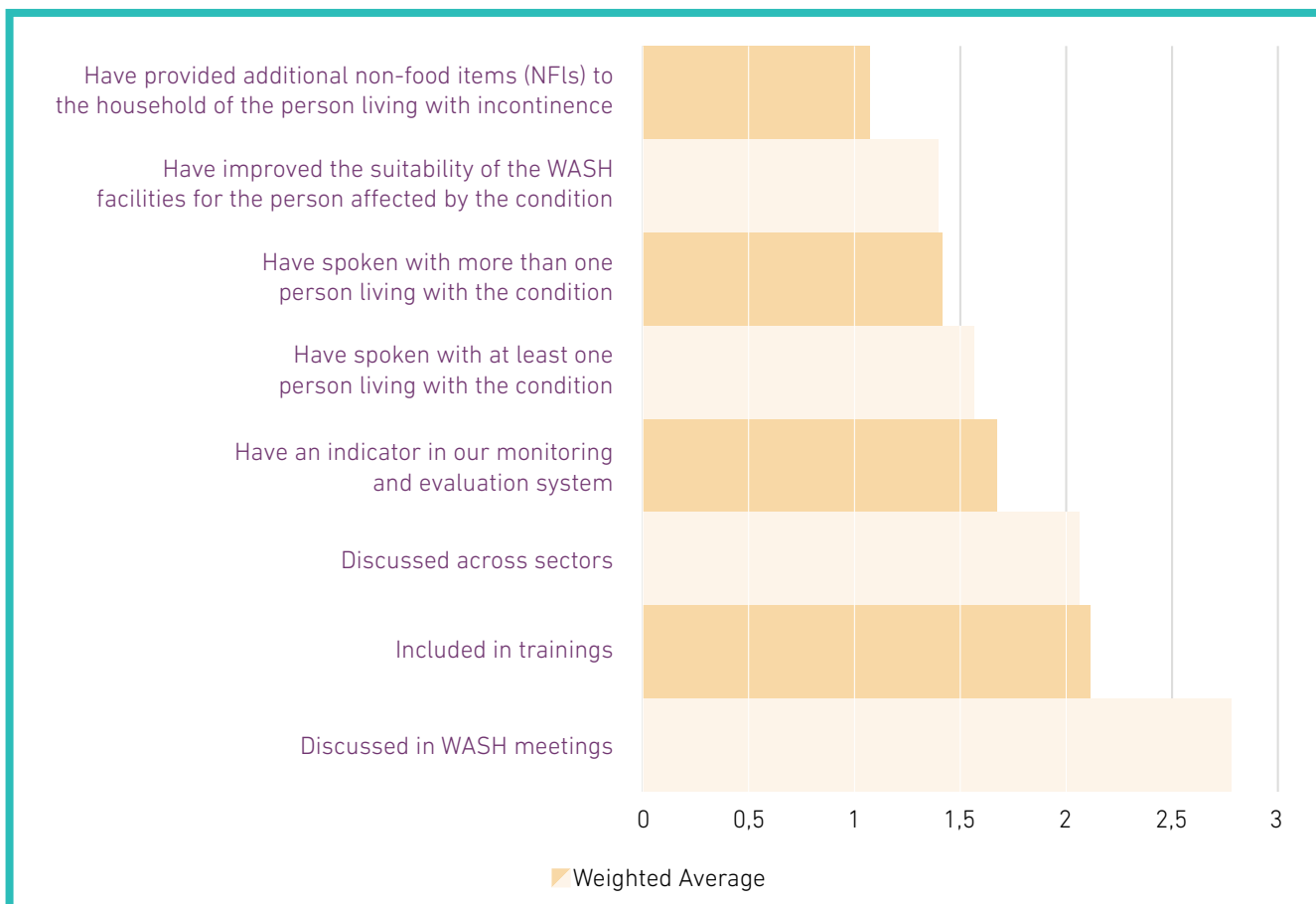
knowledge on this issue. Considering that some of the NCA teams have been working on this issue and other teams have not worked on it, this range of responses makes sense.

QUESTION 2 - CONSIDERING ANY NCA PROGRAMME YOU HAVE BEEN INVOLVED IN – INCONTINENCE HAS BEEN DISCUSSED, OR ACTIONS TAKEN TO SUPPORT PEOPLE LIVING WITH IT, IN THE FOLLOWING WAYS

8 options were provided, against which each has to be scored against this scale:

| 1 Never | 2 Once | 3 Occasionally | 4 A few times | 5 Regularly | N/A |
|------------|-----------|-------------------|------------------|----------------|-----|
|------------|-----------|-------------------|------------------|----------------|-----|

Considering any NCA programme you have been involved in - incontinence has been discussed, or actions taken to support people living with it, in the following ways
(Longer the bar, the more common the action occurs)



In terms of actions undertaken so far, more people have been involved in discussions on the subject in WASH meetings or in trainings or discussed across sectors, but only occasionally. Only a few shared that they had undertaken actions related to incontinence, such as providing NFIs or improving WASH facilities for a person affected by this condition.

In terms of having spoken with someone with

incontinence, out of 18 respondents: 12 people responded never, 3 said only once, and 3 people said occasionally. This is an important finding, as an important step in the process of learning about this subject, is to hear from people living with incontinence themselves. Hence, facilitating opportunities for staff and partners to learn from people themselves, would be a useful step in building understanding and confidence, as part of capacity building processes.

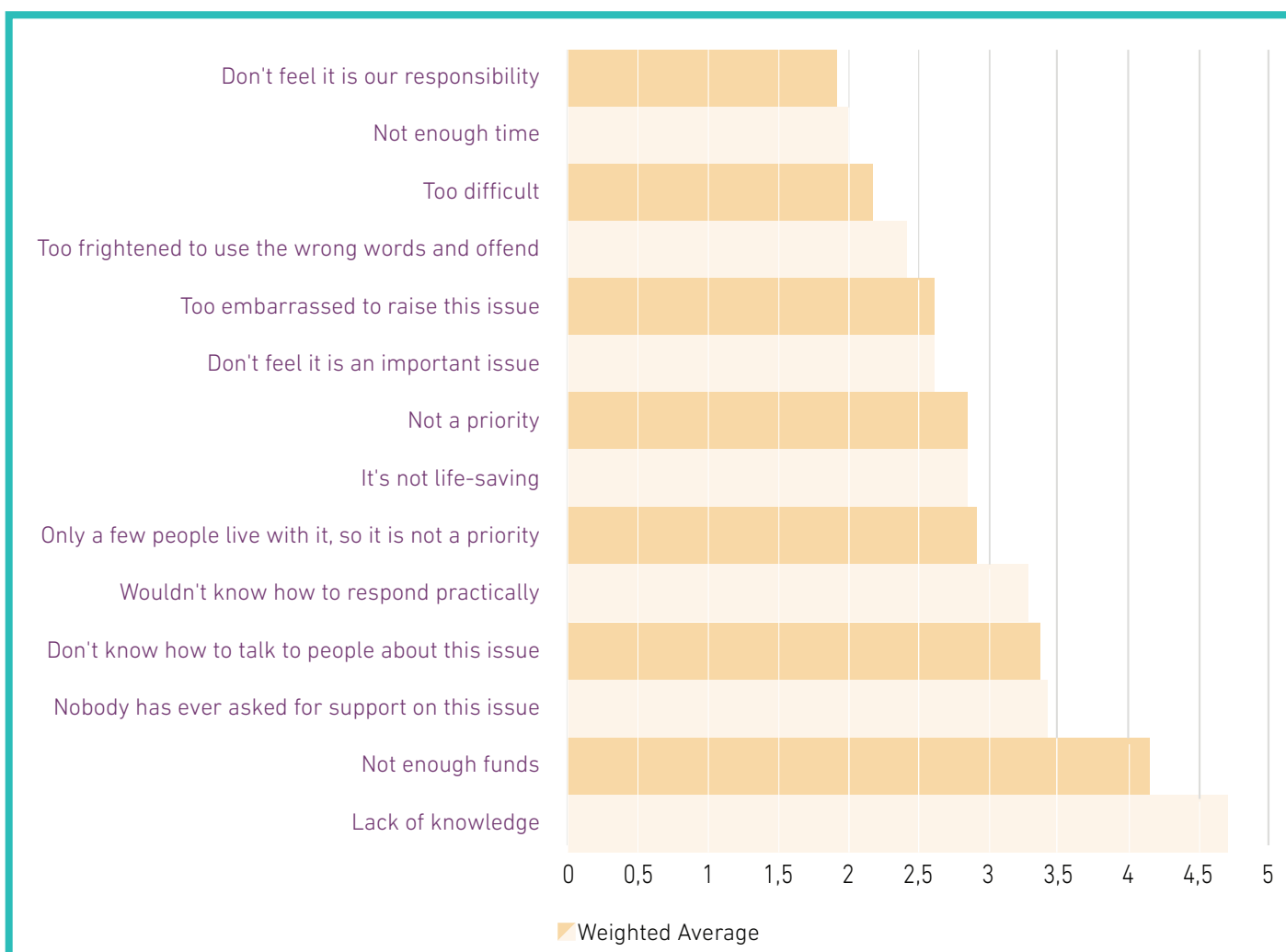
QUESTION 3 - PLEASE RANK THE FOLLOWING BARRIERS TO ENGAGING WITH PEOPLE WITH INCONTINENCE IN NCA'S HUMANITARIAN RESPONSES

14 options were provided, against which each has to be scored against this scale:

| | | | | | |
|------------------------|--------------------------------|----------------------------------|---------------------------|--------------------------------|---|
| 1 No barrier | 2 Occasional barrier | 3 Quite common barrier | 4 Large barrier | 5 Very large barrier | 6 One of the largest barriers |
|------------------------|--------------------------------|----------------------------------|---------------------------|--------------------------------|---|

Please rank the following barriers to engaging with people with incontinence in NCA's humanitarian responses

(Longer the bar, the more significant the barrier)



The key barriers to engage with people with incontinence in humanitarian responses, revolve around a lack of knowledge, lack of funds, not knowing how to talk about the subject, or how to practically respond. The next group of barriers, included not believing it is an important or priority issue and feeling that it is not life-saving and the next group are around feeling embarrassed to talk about the subject and not wanting to offend. The last group, and hence the least barriers as

assessed by the respondents, are around it being too difficult, not having enough time and it not being our responsibility.

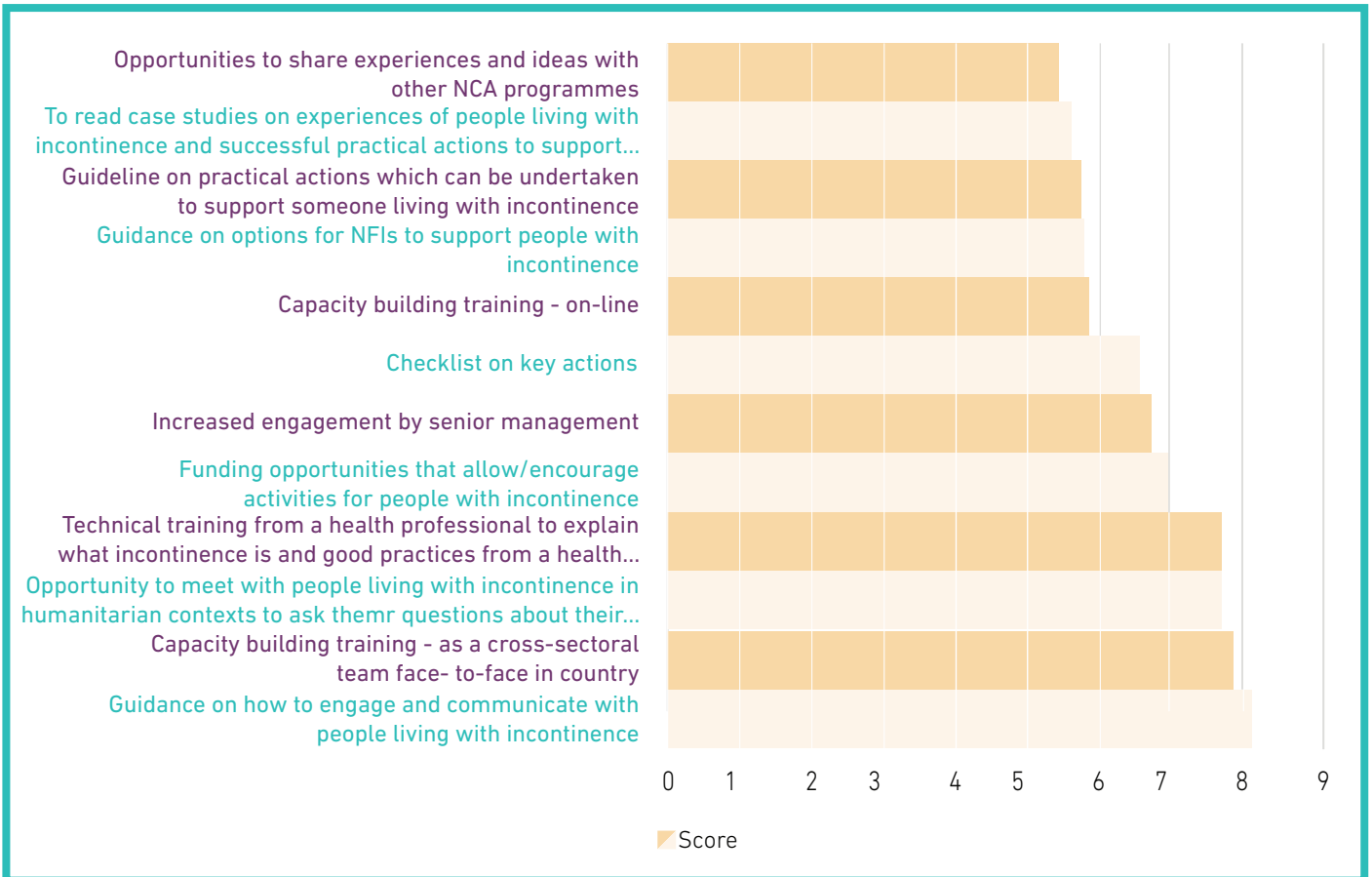
It is expected that the key barriers will all be possible to respond to, through the development of guidelines, tools and capacity building, as well as increasing commitment of senior management and donors, in order to increase funding availability.

QUESTION 4 - What support or actions would help your programme to be able to strengthen engagement with and support more people with incontinence?

Please rank the following 12 options, from 1 to 12, where 1 would be the most useful and 12 the least useful



What support or actions would help your programme to be able to strengthen engagement with and support more people with incontinence? (Shorter the bar, the higher the priority)



In terms of support or actions to be able to strengthen engagement with and support more people living with incontinence, the responses were overall, pretty even when considering the weighted average responses. This means that people gave different combinations of answers.

Opportunities to share experiences with other programmes, to see case studies, showing how this issue had been practically responded to and guidelines, checklists and capacity building were the highest ranked priorities. But following not far behind is increased engagement by senior management and funding opportunities.

Annex III

Guidance, research, capacity building

III.1 GUIDANCE

The following list provides key examples, roughly in date order, where incontinence has been mentioned in guidance of relevance to the humanitarian sector, over the years:

- 2007 - OXFAM-GB (2007) **Excreta disposal for physically vulnerable people in emergencies**⁵⁸
- Includes mention of use of bed pans and urine containers as well as toilet chairs
- 2012 - House, S, Mahon, T, Cavill, S (2012) **'Menstrual Hygiene Matters; A resource for improving menstrual hygiene around the world'**, WaterAid (co-published by 18 organisations)⁵⁹
- Includes a short section, p320, section T7.3.2 **'Incontinence, fistula, post-natal mothers and sanitary protection'**
- 2013 and 2016 - House, S (2016) **Considerations for selecting sanitary protection and incontinence materials for refugee contexts**, UNHCR⁶⁰ - Developed initially for IRC in 2013 and modified/updated for UNHCR in 2016
- 2014 - USAID/WASH Plus Project (2014) **Integrating safe water, sanitation and hygiene into HIV programmes, A training and resource pack for Uganda**, November 2014⁶¹ - Includes some great simple guidance with images on how to care for someone with HIV who is bed bound
- 2015 - 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 fecal incontinence in low- and middle-income countries**, WaterAid and SHARE Research Consortium⁶²
- 2016 - 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. and House, S. (2016) **'Incompetent at incontinence - why are we ignoring the needs of incontinence sufferers?' Waterlines**, 35(3)⁶³
- 2017 - UNHCR (2017) **Protection, Accountability and WASH, Briefing note**⁶⁴ - Incontinence incorporated into the section on MHM
- 2018 - 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**⁶⁵ - This is a great document and very practical, and includes some other really useful info related to support for hygiene for people with disabilities, including how to carry people for example and aids to do so



'Incontinence: We Need to Talk About Leaks'

Frontiers of Sanitation: Innovations and Insights 16
Sanitation Learning Hub, Institute of Development Studies
<https://sanitationlearninghub.org/resource/incontinence-we-need-to-talk-about-leaks/>

- 2019 - 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 - The set of four documents – a) Guidance document, b) 4-page Summary of the guidance document, c) Case Studies; and d) References⁶⁶
 - 2020 - 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*⁶⁷ - This document includes updated guidance on learning and good practices from more recent research and has useful sections with tips on how to talk about incontinence or leaks.
 - 2022 - **Fact Sheet on supporting people with incontinence from the WASH perspective** - By the Red Cross and Red Crescent Movement. Currently the Incontinence fact sheet is available in English, but will be available in Spanish and French in December 2022 and an Arabic translation in early 2023.⁶⁸
- **in Emergencies – Bangladesh**⁷⁰ - mentions incontinence and adaptations for accessibility - pp 107, 115 and 120-124
 - 2018 - WASH Sector Cox's Bazar (2018) **WASH Sector Strategy, Cox's Bazar Rohingya Refugee response** – mentioned on p20
 - 2018 - Age and Disability Consortium (2018) **Humanitarian standards for older people and people with disabilities** – Mentioned on pp124-134⁷¹⁷²
 - No date - UNHCR (no date) **Working with Older Persons in Forced Displacement** – Has a mention on p20⁷³

EXAMPLES OF RECENT UPDATES TO FISTULA GUIDANCE:

EXAMPLES OF STANDARDS, STRATEGIES AND GOVERNMENT GUIDELINES:

- 2015 - Inter-Agency Standing Committee (2015) **Guidelines for Integrating Gender-Based Violence Interventions in Humanitarian Action** – Included on pp 283 and 292⁶⁹, discussion on discrete provision of hygiene and dignity kits and need for better access to WASH facilities for males and females who have suffered trauma due to rape and hence have incontinence
- 2017 - Government of the People's Republic of Bangladesh, Ministry of Local Government Rural Development & Cooperatives, DPHE and Department of Disaster Management (2017) **Operational Guidelines for WASH**
- 2018 - WHO (2018) **Recommendation on the length of bladder catheterization following surgical repair of a simple obstetric urinary fistula**⁷⁴- Updated good practice
- 2021 – UNFPA (2021) **Guiding principles for clinical management and program development - Obstetric Fistula & Other Forms of Female Genital Fistula**⁷⁵- This updated guidance builds on lessons learned over the past decade-plus and details new evidence-based strategies and approaches to end fistula.

There are also a wide range of guidance documents on design of WASH adaptations for people with disabilities in LMICs, which have been prepared after the publication of the Jones and Reed (2005) **Water and sanitation for disabled people and other vulnerable groups: Designing services to improve accessibility**⁷⁶. Plus, a range of websites, with useful information, coordinated by CBM, the International Disability Alliance, WaterAid Australia and others. Refer to **Supporting document 1** - for more information and links.

III.2 RESEARCH FROM LMICS AND HUMANITARIAN CONTEXTS

This section provides examples of research which has specifically focused on incontinence in LMICs or humanitarian contexts. Each piece of research, is providing increasing levels of evidence, on the basis of which advocacy can be undertaken to encourage increased engagement in this area.

COMPLETED DESK STUDIES AND MASTER'S AND PHD THESES

- A desk study by Chelsea Giles-Hansen (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'** - This was the first study focusing specifically on incontinence in humanitarian contexts⁷⁷
- A Master's thesis (2017) undertaken by Clare Rosato-Scott, while at Cranfield University on **'Incontinence in Zambia: Understanding the coping strategies of sufferers and carers'**⁷⁸
- A Master's thesis (2017) undertaken by Zara Ansari, at LSHTM on **'Understanding the coping mechanisms employed by people with disabilities and their families to manage incontinence in Pakistan'**,^{79,80}
- A PhD thesis (2019) undertaken by Amita Bhakta, at WEDC, Loughborough University, on **'Opening the doors to the water, sanitation and hygiene needs of women from the onset of the perimenopause in urban Ghana'**⁸¹ – This thesis focusses on a range of issues including MHM, bathing, laundry and also incontinence. Discussion relating to perimenopause and incontinence in depth can be found on p.190, p.223, p.250-onwards, p.255

Planned and on-going Master's and PhD theses

- A PhD thesis (on-going) undertaken by Clare Rosato-Scott, at Leeds University on **children with incontinence in humanitarian settings**. Examples of research undertaken as part of this research:
 - **"Urinary incontinence in children aged 5 to 12 in an emergency setting: lessons learned in Ethiopia"**⁸²
- In Tampere University, Finland, the Pad Project (www.padproject.online) conducts academic research relating to sustainable continence care and practices of humanitarian aid. Presently, there are three MA theses under preparation under the auspices of the project. The studies are conducted by three health professionals and MA students in the Public Global Health program, and published as MA theses in 2023:
 - Silja Talvinen – is focusing on **incontinence issues inflicted by sexual violence, and how it is voiced out, encountered and treated in humanitarian emergencies**
 - Karolina Himanen – is investigating **the relationship between female genital mutilation or cutting (FGM/C) and incontinence and care practices in the particular context of humanitarian aid**
 - Elina Sirén – is looking at **the intersections of violence and incontinence in the lives of persons with disability in humanitarian spaces**

ONGOING OPERATIONAL RESEARCH

- OXFAM and HelpAge have been undertaking some operational research on **home-based sanitation for people with mobility issues who cannot use latrines**. The OXFAM team working in the IDP camps in Myanmar near the border with Bangladesh, reached out to the residents of this camp to ask about incontinence issues, when looking at **possible solutions for home-based care**.

WATER, WOMEN AND DISABILITY STUDY, VANUATU - WORLD VISION AND LSHTM

World Vision and London School of Hygiene and Tropical Medicine and partners, undertook an important study in 2019⁸³, on large scale on MHM and incontinence for people with disabilities across Vanuatu. Vanuatu is an Island state in the Pacific, which is affected by natural disasters. The study asked similar questions to people with and without disabilities, so there is a range of useful data and qualitative findings.

A FEW KEY FINDINGS INCLUDED:

Approximately one third of people with disabilities and one quarter of people without disabilities included in the case control study, reported experiencing incontinence, urinary or faecal, at least three times a week.

The Water, Women and Disability study in Vanuatu, findings on disability prevalence are based on data collected from 56,402 individuals across SANMA and TORBA provinces in Vanuatu, from 11,446 households.

In addition, a case-control study of 1,516 participants was also carried out – meaning that a sub-sample of survey participants identified as having a disability age 5+ and an equal number of people without disabilities were examined more closely. This was to assess differences in WASH access and experiences about a range of topics such as education, menstrual hygiene and incontinence explored by the study.

- People with disabilities were twice as likely to experience incontinence as people without.
- Approximately half of people with disabilities said that they were unable to wash and change in privacy whilst at home. This is in comparison to people without disabilities, where almost all reported being able to wash and change in privacy when they experienced incontinence at home.
- Women with disabilities and people with mobility limitations reported a greater likelihood of experiencing urinary incontinence than other people with disabilities.
- Carers of people with incontinence reported limiting people's consumption of food and water, in order to reduce the number of times the person needs to urinate, and to manage weight gain.

For more information on the study and its findings see: MH and incontinence findings from the Vanuatu study on YouTube: <https://www.youtube.com/watch?v=030UQInPyWk> and an infographic: <https://www.lshtm.ac.uk/sites/default/files/2022-01/WWD%20-%20Incontinence.pdf>.

The research was funded by the Water for Women Fund, funded by Australian Aid and partners involved included:

- World Vision
- Vanuatu Society for People with Disability (VSPD)
- Disabled Persons Association (DPA)
- London School of Hygiene and Tropical Medicine (LSHTM)
- Vanuatu National Statistics Office
- Ministry of Justice and Community Services
- Sally Baker (independent consultant)
- Quantitative research team (50 enumerators and three field supervisors)
- Qualitative research team: Judith Lakavai, Sannine Shem, Headly Aru

ELRHA / HUMANITARIAN INNOVATION FUND RESEARCH ON INCONTINENCE IN HUMANITARIAN CONTEXTS

ELRHA's Humanitarian Innovation Fund (HIF) funded three research studies focusing on people living with incontinence in humanitarian contexts. These three studies are shown below in the table which follows. The completion of these studies was

delayed due to the Covid outbreak, but all teams still managed to complete.

These studies are important studies in relation to incontinence in humanitarian contexts, because these are the first studies, which have looked at this issue of incontinence in humanitarian contexts specifically.

TABLE 1- OVERVIEW OF ELRHA/HIF RESEARCH INTO INCONTINENCE IN HUMANITARIAN CONTEXTS

| NAME | PARTNERS | PUBLISHED FINDINGS |
|--|--|---|
| Learning on the experiences of older people living with incontinence in humanitarian contexts in Malawi and Ethiopia | <p>LEAD: OXAM-GB</p> <p>PARTNERS:</p> <ul style="list-style-type: none"> • HelpAge • Institute of Development Studies • Malawi Network of Older Persons Organisations, MANEPO • St John of God Hospitaller Services, Malawi • Federal Ministry of Health, Ethiopia • Gambella University | <p><i>Research was undertaken in Gambella, Ethiopia and Blantyre, Malawi. The final report is not yet published, but the following provide some information on the learning which occurred during this research:</i></p> <ul style="list-style-type: none"> • <i>OXFAM and HelpAge, Humanitarian Innovation Fund (HIF) funded research project 'Improving the lives of older people – Understanding the barriers to inclusion of older people with incontinence in humanitarian WASH programming' - Desk study, https://drive.google.com/file/d/13HZE_1lxVgQ71hfsNZg5oBCmnuj7H_Ge/view?usp=sharing</i> • <i>Presentation to the Emergency Environmental Health Forum, 2022 - https://www.youtube.com/watch?v=P2x8dW8dDf4</i> |
| WASH programming for women with obstetric fistula induced incontinence in Ghana | <p>LEAD: Research and Grant Institute of Ghana (ReGIG)</p> <p>PARTNERS:</p> <ul style="list-style-type: none"> • Coalition of NGOs in Water and Sanitation (CONIWAS) • Fistula Foundation of Ghana • UNFPA, Ghana | <p>FINAL REPORT:</p> <p>Research and Grant Institute of Ghana (ReGIG) (2022) <i>Water, Sanitation and Hygiene (WASH), programming for women with obstetric fistula-induced incontinence in Ghana</i>, HIF/ELRHA, https://drive.google.com/file/d/1tuCsWbyOMR-LPcpL1IP299El_HWSSBJ_/view</p> |

| NAME | PARTNERS | PUBLISHED FINDINGS |
|--|--|--|
| <p>Understanding the experiences of children with incontinence, and their caregivers</p> | <p>LEAD: Leeds University / The University of Western Australia</p> <p>PARTNERS:</p> <ul style="list-style-type: none"> • University of York • Plan International, Uganda • Uganda Christian University • World Vision, Bangladesh • UNICEF, Bangladesh | <p><i>Research was undertaken with children and their caregivers in Adjumani District, Uganda and Cox's Bazar, Bangladesh. A summary of the findings is available here:</i></p> <ul style="list-style-type: none"> • https://www.waterwomenworld.com/wordpress/wp-content/uploads/Appendix-2-Summary-of-findings.pdf <p><i>All outputs from the project, including the data collection tools (e.g., the Story Book methodology) in a variety of languages are being made available, as they are published at:</i></p> <ul style="list-style-type: none"> • https://www.waterwomenworld.com/incontinence/children-and-self-wetting/ |

All three research teams also presented on the progress of their research during a **WASH Cluster Hygiene Promotion Group webinar: 'Incontinence in humanitarian settings'** on 3/3/22. The whole webinar lasts for 1 hr 17.5 mins – for individual timings of the separate presentations, refer to **Supporting document 2**.

A number of photographs and quotations from the studies above, have been incorporated into this mapping report in other sections, and a few of the most interesting aspects of the learning from the studies are included below.

REGIG LED - WASH PROGRAMMING FOR WOMEN WITH OBSTETRIC FISTULA INDUCED INCONTINENCE IN GHANA

This study investigated the lived experiences of women with obstetric fistula-induced incontinence, how they meet their WASH needs, the barriers they encounter, and existing and new interventions to improve their WASH. Questionnaires were used with 40 women with obstetric fistula at Mankessim fistula treatment centre in Ghana and two FGDs were undertaken and 30 in-depth interviews conducted.

Some of the important findings from this study included:

Psychological challenges and stigmatization

- People facing this condition face a number of psychological challenges, such as depression and some have contemplated suicide, but psychosocial support was not available and there were no systems for this and reintegration into their families. Spouses also neglect them and there are cultural implications – for men they say *“Why should I be with her, if I can get another wife?”* Nurses even do not know how to manage leakage and some nurses even stigmatise the fistula patients. Some people may also believe that you become incontinent due to a demonic or super natural force – that you are unclean and are being punished for your activities. There needs to be awareness creation to reduce stigmatization around this condition.

WASH issues

– These are big problems for women with fistula who live in vulnerable places and who do not have access to care or materials - they use local materials such as cloth or rice sacks to try and cope. And some use practices such as eating bread, which constipates them, which reduces the problems with fecal incontinence and some use Imodium which hardens their stools. They also need detergent and soap so as to not smell – so they need to buy this with money and frequent bathing and washing. One woman could not get

soap for a week, so tried to dry her items, but the smell does not go away – so it was really a challenge. Sometimes women also send children and pay them to collect water.

Operations for fistula - are also not always successful, and damage can also occur to the urinary system from this operation, leading to continued struggle for the women concerned. But when operations are successful, this can change the life of women who have been lucky enough to have had one.

OXFAM-GB LED - LEARNING ON THE EXPERIENCES OF OLDER PEOPLE LIVING WITH INCONTINENCE IN HUMANITARIAN CONTEXTS IN MALAWI AND ETHIOPIA

This research study aimed to develop a practical and sensitive methodology to understand the scope and scale of incontinence and how it affects older people living with it and their caregivers in humanitarian contexts. A series of tools were developed, which included both qualitative tools, such as for use in focus group discussions and through in-depth interviews, with in some cases the integration of participatory exercises, such as ranking of NFIs (see the photo below) and a number of other exercises, such as soul-mate interviewing. These tools have already been shared with a number of other agencies, and there is an intention to publish them. A total of 19 FGDs, 9 small group discussions, 40 household visits, 9 community leader FGDs/KIIs, and 16 sector KIIs.

Particularly interesting aspects of this research included:

Quantitative needs assessment survey - In addition, a number of quantitative questions were also established, to try and test whether it would be possible to gather useful information on incontinence, by adding them into a rapid needs assessment survey. This was an open question at the beginning of the process, due to the perceived sensitivity of the subject. The team showed through these trials, that it is possible to gather useful information through quantitative surveys, as well as through qualitative discussions and exercises.

Feedback visits – Another interesting and positive component of this research, was that after the team had completed the first round of interviews and exercises, they then compiled the findings. They then returned to the same interviewees, to provide feedback. They also used this opportunity to check the validity of their findings and also to take the discussions a step further, with additional exercises, such as ranking of NFIs, or discussing some of the findings in more depth. The team found that people tended to open up more on the second visit. This might be a feature, of trusting the team more, as they agreed with the findings they found and also as they saw the effort, they made to return to update them, which in itself is quite an unusual step for research processes.

Involvement of a mental health specialist – This research project was very unique in that the team also included a mental health specialist, from St John of God Hospitaller Services (SJOG) in Malawi. SJOG run the mental health services for half of the whole of Malawi, on behalf of the Government of Malawi. The reason, it was decided to invite a mental specialist to be part of the team, was because some older people, suffer with dementia, and this makes managing toileting and incontinence very challenging. Hence, by having a team member with this specialisation, it was to better understand how to communicate with people with dementia and their caregivers, and also more effectively learn what as WASH specialists we should be doing to assist. Quite a lot of learning also went into this aspect and also that of violence towards older people, during the desk study, which can be viewed here⁸⁴. See **Section 3.3.2** – for examples of this learning⁸⁵.

LEEDS UNIVERSITY / THE UNIVERSITY OF WESTERN AUSTRALIA LED - UNDERSTANDING THE EXPERIENCES OF CHILDREN WITH INCONTINENCE, AND THEIR CAREGIVERS

This research project aimed to understand the barriers to inclusion and well-being that those living with incontinence, particularly children aged five to 11 and their caregivers, face in humanitarian contexts, so that more holistic, effective and inclusive WASH and protection programming can be developed. A participatory research method was developed to work with children, their caregivers, and other stakeholders in Cox's Bazaar refugee camps, Bangladesh and refugee settlements in Adjumani District, Uganda. In Bangladesh, the local team chose to not identify children living

with incontinence, or their caregivers, to ask them questions about their experiences, due to concerns over causing stigma, and so instead to involve groups of children or caregivers in participatory exercises, who may be or may not themselves not be living with or managing incontinence. In Uganda, the local team chose to identify children likely to be living with urinary incontinence for inclusion in the study.

Interesting aspects of this research included:

- **The participatory tool** – This was developed to promote discussions with the groups of children, involved the use of a story book and a process where the children were involved in drawing as part of the process. From the provisional findings so far, the method has led to a range of useful learning, around the children's perceptions of what they would feel like if self-wetting, although the testing process led to suggestions to simplify the use of the tool for future exercises. The tool was not developed to share personal experiences of self-wetting, but experiences of a character self-wetting in different scenarios.
- **Frustrations of caregivers** – Findings were also identified around the frustrations of caregivers who would have to do more laundry, if their child self-wets and also the risk of physical abuse from caregivers to children if they self-wet themselves. Caregivers reported feeling a range of emotions due to the child's self-wetting, including those related to anger and distress at the extra washing, and concern over whether they may be able to get married when they are older. Teachers and peers also responded negatively to children self-wetting.
- **Inappropriateness of the WASH facilities also caused concerns** – This was with distance causing a barrier, and some caregivers give buckets to their children to use in their home at night, to prevent the journey to the latrine. In Cox's Bazar, there are multiple challenges for children to use the toilets, due to distance, lights, difficult road conditions and constraints on their mothers to accompany them to the toilet, hence resulting in urination around the shelters. In Uganda, some mattresses with protective sheeting have been observed, but bed pads were not well known.

- The team highlighted that social incontinence (that is, children who wet themselves because they are not able to, or do not want to, use the sanitation facilities available) in children aged five to 12, is best managed during an emergency by providing sanitation facilities that children want, and are able, to use. But that there will always be children that wet themselves, due to experiencing either social incontinence (despite best efforts, some children may just never feel comfortable enough to use public latrines, especially at night) or UI.
- They propose that communication to support the normalization of the condition, will be a critical first step to be taken, and can be as simple as educating humanitarian practitioners across sectors on the condition so that they can spread positive messages about it. The inclusion of products in standardized hygiene kits to support the management of self-wetting would also help, notably mattress protectors and extra supplies for washing including buckets, soap and washing lines.

NOTE ON OTHER REASONS THAT CHILDREN MAY WET THEIR BED AND LIVE WITH INCONTINENCE

In addition, to the learning from the research above, please refer also to other case studies in this mapping report, which identify, from the experiences of a number of different humanitarian agencies working on the ground in multiple humanitarian responses, that children also wet their bed, due to experiencing traumatic events, such as due to conflict, or due to having experienced other distressing experiences, such as travelling in small boats in rough seas, to reach Europe. Bed wetting is reported as a bigger problem in emergency contexts, where conflict has been experienced. This may for example, lead to nightmares. In addition, children may also have a medical condition, including genetic conditions, which can also lead to incontinence.

Refer to: **Supporting document 1 – CS-GHA-A; CS-GHA-F; CS-GHS-G**

III.3 CAPACITY BUILDING, WEBINARS AND PRESENTATIONS

A number of opportunities for raising awareness and capacity building on incontinence have occurred over the past few years. In addition, to the presentations and webinars already mentioned in earlier sections, such as those connected to the ELRHA/HIF research findings, a few other examples include:

- **Incontinence integrated onto MHM or other sessions** - For a number of years, short discussions on incontinence have been added into training sessions, where MHM or equity and inclusion have been discussed. Using a few NFIs, such as urine containers or different kinds of reusable incontinence underwear, or disposable pads for incontinence, have been useful tools around which to promote discussion.

INTEGRATING INCONTINENCE INTO PARTICIPATORY ROLE PLAYING

One exercise, used as part of the SaniTweaks training, is that of artificially disabling a number of the participants, to then undertake a roll play of using a squat latrine. The other participants watch the actors who have been artificially disabled, and observe the difficulties they face using the squat toilet. One of the actors is asked to walk slowly like an older person who is unstable on their feet and they leak water to represent incontinence. OXFAM tries to encourage people to consider what it would be like to stand in other people's shoes. Discussion is then facilitated on this issue and the difficulties of living with it, in a humanitarian context.

- **A one-day training on WASH for women going through the peri-menopause** – This was run as a collaboration between Dr Amita Bhakta and the Rural Water Supply Network in 2022. This was not humanitarian contexts focused, but women going through the menopause process live in all contexts, and it is understood that incontinence is discussed in the training.
- **OXFAM has been running SaniTweaks trainings** – These have been for its own staff and also for humanitarian actors from other agencies, in multiple responses around the world. The principle behind the SaniTweaks concept, is that designing toilet facilities, should not be a one-off exercise, but requires on-going engagement with the users, and to seek design ideas and feedback, after which improvements should be made. It was also observed, that the experience has been that there is not really stigma within the practitioners, and people are interested to learn about this issue.
- **IFRC** – They have been trying to integrate incontinence into their wider trainings, so as to not overwhelm participants, as they also do with MHM.
- **Absorbent products** - A series of MOOCs have also been prepared to support the release of the new Training in Assistive Products (TAP) series, prepared by WHO, to introduce assistive products from the Priority Assistive Products Lists (APLs). One of these MOOCs is on the subject of Absorbent Products, which are used for the management of incontinence. These MOOCs are free to participate in and can be undertaken on a range of different subjects. <https://www.who.int/news-room/events/detail/2022/11/10/default-calendar/launch-of-who-training-in-assistive-products>
- **A series of trainings have also been run on Fistula surgery over the years** – These aim to improve the quality of knowledge of surgeons performing fistula surgeries. See **Annex II – CS-GHA-H** - for more details.
- **A half day training event was run in the WEDC conference, Loughborough University UK, in 2017**, on incontinence in low-income contexts – This session organised by Leeds University, IMPRESS Network and Cranfield University, with inputs also from London School of Hygiene and Tropical Medicine, Norwegian Church Aid and Plan International. **NCA has developed an online training on MHM and incontinence** - This is available to any interested participants: <https://fabo.org/nca/NCAWebinarSeriesMHM>

Examples of other webinars and presentations –

- UNICEF Supply Division, ran a webinar to increase awareness on this issue among its network through Assistive Technology advocacy webinars, which are held on a quarterly basis. In coordination with WHO, a presentation on incontinence was conducted in October, 2022
- The London School of Hygiene and Tropical Medicine, Environmental Health Group, ran a webinar on incontinence in Sept 2020, to raise awareness on a possible new subject for research.
- Michelle Farrington, of OXFAM - presented the findings at the Emergency Environmental Health Forum; at the UNC (2021); Global WASH Cluster (GWC) Satellite events (2021); IMechE conference (2021); and at a UNICEF conference on inclusion (2022)
- A meeting was facilitated on incontinence for the IRC Health Unit, in December 2022, to introduce the subject of incontinence and to present the provisional findings of the NCA mapping process and promote discussion.

“As soon as you mention it, people become interested”

In response to the question about the specific challenges with getting WASH actors to engage with incontinence, one respondent shared, that most WASH actors have not even thought about it, as the issue is hidden in communities.

“It is a subject that is taboo to talk about, but as soon as you mention it, people become interested. They just lack knowledge, but they often have it either themselves or have a family experience of it, but they have not put two and two together”.

(Disability and WASH Specialist)

III.4 OPPORTUNITIES FOR LEARNING FROM MHM AND OTHER ACTIONS

A number of examples were shared, where lessons, might potentially be useful also for the scaling up of incontinence efforts.

TABLE 2 - LESSONS FROM BROADER ACTIONS FOR INCONTINENCE FROM MHM AND OTHER ACTIONS

| ACTIVITY | POSSIBLE LESSON AND DISCUSSION |
|--|--|
| Annual MHH in Schools webinar event | <p>This annual event, offered opportunities for people working on MHM on the ground to document and share their experiences, as well as academics working on MHM. The organisation of such an event, is however quite substantial and would require quite significant funds to pay for.</p> |
| Progress on MHM in humanitarian response | <p>HISTORY ON MHM IN HUMANITARIAN RESPONSE – FROM 1997:</p> <p>Early efforts to start discussing MHM related to humanitarian response started in around 97. Tearfund published an article on a woman who was living in Bangladesh who was washing her menstrual pads and then putting the wet pads into a plastic bag under her bed, until they were needed again, which means they were becoming moldy. In response to becoming more aware of the significant gaps related to MHM support in humanitarian contexts after reading this article, an effort was made through discussion between Sarah House, of WEDC, at Loughborough University, and John Adams, of OXFAM, to get MHM mentioned in the first 'blue' version of Sphere in 1997.</p> <p>A few actors started to try and modify their responses, including OXFAM, through the provision of screened washing and drying areas in the Pakistan earthquake response in 2006, and MHM started to be integrated into some emergency WASH trainings, including those run by REDR. A section on MHM in emergencies, was included in Menstrual Hygiene Matters, which was co-published by 18 agencies in 2012. But it was challenging to find examples at this stage of how MHM was being responded to in emergency contexts.</p> <p>Following this, and continued advocacy for improvement in responding to MHM in emergencies, including with the International Rescue Committee (IRC), the IRC then established a partnership with Columbia University to develop a separate stand-alone, Toolkit for MHM in Emergencies⁸⁶, published by 27 agencies, in 2017. Various actors had also started working more on this issue, including the IFRC and the Red Cross and Red Crescent Movement, who undertook on-the ground research in Burundi, on the use of washable/reusable sanitary pads and associated NFIs. They published on this research and started training members of the RCRC Movement and others.</p> <p>The time period between the first discussions on the need to integrate MHM in humanitarian responses, therefore took about 20 years - to the point at which the standalone, cross-sectoral toolkit was published.</p> |

| ACTIVITY | POSSIBLE LESSON AND DISCUSSION |
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| <p>Progress on MHM in humanitarian response</p> | <p>MHM in emergencies 2022 – 25 years since the initial discussions:</p> <p>In MHM there is more recognition of need, but not yet fully clear on the practicalities, with the menstrual barrier preventing access to services. Recognition has occurred that not everyone has been given support equally, but there is increasing progress in relation to supplies, such as in coordination of health supplies and undertaking surveys of their distribution. But the M&E systems are not yet in place to monitor actions.</p> <p>Leadership for MHM:</p> <p>Leadership on MHM for implement in responses is still not clear. For example, is a WASH and Education Officer the most appropriate to provide leadership? Where does their responsibility stop and start? These questions lead to a lack of accountability and apathy.</p> <p>The MHMiE Toolkit has been a significant help, because it provides a breakdown across sectors and suggests how to deal with intersectoral coordination, but still much work is needed in this area on the ground.</p> <p>MHM and SRH:</p> <p>A number of actors, mentioned that there has not been so much engagement by the SRH sector in MHM, as this sector have specific areas they focus on, including maternal and newborn health and safe abortions. But the SRH sector has been involved in emergency supply for staff and patients and also cover contraceptives, if not found in the area and they focus on the menstrual cycle. SRH actors also have role, with more focus on the side of menstrual disorders.</p> <p>SRH focus more on pregnancy and delivery, and hence this incontinence, should be integrated into these areas and also when focusing on the medical management of rape.</p> |
| <p>Establishment of the MHM in Emergencies working group (TWG)</p> | <p>This group was set up in 2021, through collaboration between UNHCR and UNFPA. They identified different colleagues from IOM and UNICEF across sectors, including UN agencies and INGOs. It includes health, WASH, protection and GBV and represents different clusters.</p> <p>It is aiming to develop a stronger MHM commitment and is an informal get together. They are working on tools, quality, developing strategic operational procedures. A strategy was also developed last year and they will be revising it in the coming month.</p> <p>They pick a working group under a specific sector and hold a workshop to implement them and then hold an intersectoral work group – and cluster coordinator has action plan and the group reports back on progress.</p> |

| ACTIVITY | POSSIBLE LESSON AND DISCUSSION |
|--|--|
| <p>Establishment of the MHM in Emergencies working group (TWG)</p> | <p>The strengths of having an UN-led working group, is that it will hopefully encourage more commitment from the UN agencies, and will hopefully lead to more coherence, both of which are needed to take issues to scale.</p> <p>The downsides include the sustainability of the group, if/when people move on or organisational priorities change, and the group therefore becomes less functional.</p> <p>The coordination for MHM, could also be an opportunity for increased discussion on incontinence across agencies, including because this subject is already combined with MHM in Sphere. But this would not be the only location, where incontinence would need to be discussed, as it will also need to be integrated into other coordination mechanisms, including for example, those related to GBV and to disability.</p> <p>This group was set up in 2021, through collaboration between UNHCR and UNFPA. They identified different colleagues from IOM and UNICEF across sectors, including UN agencies and INGOs. It includes health, WASH, protection and GBV and represents different clusters.</p> <p>It is aiming to develop a stronger MHM commitment and is an informal get together. They are working on tools, quality, developing strategic operational procedures. A strategy was also developed last year and they will be revising it in the coming month.</p> <p>They pick a working group under a specific sector and hold a workshop to implement them and then hold an intersectoral work group – and cluster coordinator has action plan and the group reports back on progress.</p> <p>The strengths of having an UN-led working group, is that it will hopefully encourage more commitment from the UN agencies, and will hopefully lead to more coherence, both of which are needed to take issues to scale.</p> <p>The downsides include the sustainability of the group, if/when people move on or organisational priorities change, and the group therefore becomes less functional.</p> <p>The coordination for MHM, could also be an opportunity for increased discussion on incontinence across agencies, including because this subject is already combined with MHM in Sphere. But this would not be the only location, where incontinence would need to be discussed, as it will also need to be integrated into other coordination mechanisms, including for example, those related to GBV and to disability.</p> |
| <p>Research into MHM for girls with learning disabilities in humanitarian contexts</p> | <p>The following learning related to how to support girls with learning disabilities in their MHM, including building capacity of their caregivers, also offers lessons for how to support people with learning disabilities in managing their incontinence, where they also live with this condition.</p> |

| ACTIVITY | POSSIBLE LESSON AND DISCUSSION |
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| <p>Research into MHM for girls with learning disabilities in humanitarian contexts</p> | <p>The Bishesta campaign in Nepal⁸⁷ focused on developing methods to support girls with intellectual impairments on how to manage their MHM and to work with caregivers on how to support their daughters. This involved using visual aids, including a doll and other associated items, to teach the girls about their menstruation and how to manage it.</p> <p>The learning through this campaign, was then adapted for Vanuatu to learn how to support girls with learning disabilities, how to manage their MHM in humanitarian contexts. This has also included the training of caregivers.</p> <p>Veivanua = Vanuatu version of the Bishesta campaign. It has already since been agreed to pre-position MHM packs, for use in future emergency situations.</p> <p>The team will also be writing a Frontiers of CLTS on the how the Bishesta campaign was adapted for the humanitarian setting in Vanuatu in 2023.</p> <p>The Vanuatu Society of Disabled People (VSDP), were integral to this project and the research and are keen to get incontinence on their agenda and into their safe care programmes. The team also engaged with the gender, protection cluster in Vanuatu and disability actors during this process.</p> <p>Initial learning in Vanuatu included:</p> <ol style="list-style-type: none"> 1. Very little data and evidence exists about the experiences of people with disabilities of managing menstruation in emergencies 2. Displacement in an emergency can disproportionately affect people with intellectual disabilities' ability to manage menstruation 3. Current hygiene kit provisions do not consider the unique needs of people with disabilities and often do not include enough menstrual materials 4. Male caregivers are involved in providing MH support to people with disabilities 5. People with disabilities must participate in MH research and interventions in emergencies <p>A BLOG and paper on the learning through the study can be seen here:</p> <p>Morrison, C, Wilbur, J and Poilapa, R (2022) Menstrual Hygiene Day – Exploring the Menstrual Health Experiences of People with Intellectual Disabilities, https://www.elrha.org/project-blog/menstrual-hygiene-day-world-vision-vanuatu/</p> <p>Wilbur J, Poilapa R, Morrison C. Menstrual Health Experiences of People with Intellectual Disabilities and Their Caregivers during Vanuatu's Humanitarian Responses: A Qualitative Study. International Journal of Environmental Research and Public Health. 2022; 19(21):14540, https://www.mdpi.com/1660-4601/19/21/14540; and https://doi.org/10.3390/ijerph192114540</p> |

Annex IV

Endnotes

- 1 Credit for line image of family in a camp: Shaw, R, WEDC, Loughborough University
- 2 <https://www.yalemedicine.org/conditions/bedwetting#:~:text=What%E2%80%99s%20the%20difference%20between%20daytime%20and%20nighttime%20incontinence%3F,children%20will%20continue%20to%20have%20problems%20into%20adulthood>
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- 15 Inter-Agency Working Group on Reproductive Health in Crises (IAWG) (2018) The Inter-Agency Field Manual on Reproductive Health

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- 23** A video of the work of World Vision and partners, supporting Shirley, who has Cerebral Palsy, with a locally-made pallet chair, Vanuatu - <https://youtu.be/oYFAWw0UCiw>
- 24** This mapping process, has not considered babies as having incontinence, as their leakage of urine and faeces, is part of their developmental learning, and is seen as socially acceptable
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- 26** Adults may also face this problem due to the trauma of conflict or other experiences
- 27** This study asked questions on children with incontinence to general groups of children, not necessarily, children who themselves have experienced living with incontinence, or their caregivers. Some children may have experienced this condition, but how many were involved in the activities, is not known.
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