MAPPING OF SUPPORT FOR PEOPLE LIVING WITH INCONTINENCE IN HUMANITARIAN CONTEXTS

THROUGH THE LENS OF WASH, GBV AND ASRH

SUMMARY REPORT
DECEMBER 2022

"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".

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 led 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 has been conducted by independent consultants – Dr Sarah House and Dr Chris Chatterton.

For a list of contributors to the NCA mapping process, please refer to **Annex I**.

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.

IMAGE ON FRONT PAGE

NCA team providing support for incontinence, to older people in Mosul, Iraq
(Credit: NCA/2016)

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.

CITATION: House, S and Chatterton, C (2022) Mapping of support for people living with incontinence in humanitarian contexts, Through the lens of WASH, GBV and ASRH, Summary Report, Norwegian Church Aid

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.**

CONTENTS

INTRODUCTION 2

FINDINGS 4

NCA ENGAGEMENT 7

GLOBAL PROGRESS AND CHALLENGES 9

ADDITIONAL FINDINGS AND CONCLUSIONS
WASH 12

ADDITIONAL FINDINGS AND CONCLUSIONS
PROTECTION AND GBV 13

ADDITIONAL FINDINGS AND CONCLUSIONS
ASRH/SRH AND FISTULA CARE 13

ADDITIONAL FINDINGS AND CONCLUSIONS
HEALTH, NURSING, MIDWIFERY, PHYSIOTHERAPY AND OCCUPATIONAL THERAPY SERVICES 14

ADDITIONAL FINDINGS AND CONCLUSIONS
MENTAL HEALTH AND PSYCHOSOCIAL SUPPORT (MHPSS) 15

ADDITIONAL FINDINGS AND CONCLUSIONS
OLDER PERSONS AND DISABILITY SPECIALISTS 15

ADDITIONAL FINDINGS AND CONCLUSIONS
EDUCATION AND CHILD-FRIENDLY SPACES 16

ADDITIONAL FINDINGS AND CONCLUSIONS
CAMP MANAGEMENT, SHELTER, LOGISTICS AND SUPPLY 17

RECOMMENDATIONS 19

RECOMMENDATIONS NCA 19

RECOMMENDATIONS FOR GLOBAL HUMANITARIAN ACTORS 21

CONTRIBUTORS 22

ENDNOTES 24

EXTENDED SUMMARY

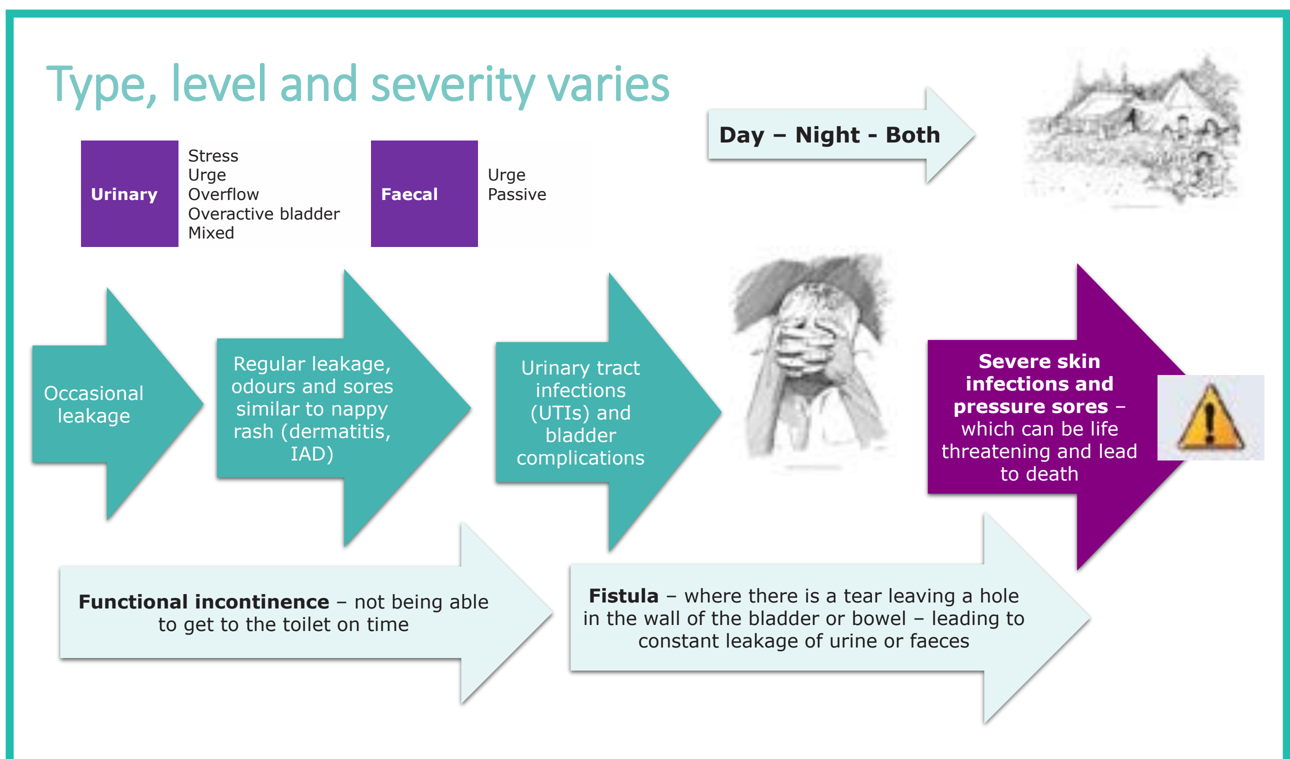
1. INTRODUCTION

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 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, or night, or both. See **Fig 1.**

> *"People's continence is the root to their dignity"*
>
> *(Humanitarian actor)*

FIG 1 - OVERVIEW OF THE RANGE OF TYPE, LEVEL AND SEVERITY OF INCONTINENCE



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 the issue of incontinence, 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 were: 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 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 initiated and led by the 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 2** - for an overview of the activities, timeline, and participants in the process.

FIG 2 - NCA INCONTINENCE MAPPING TIMELINE, PARTICIPANTS AND PROCESS[1]

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 age[2]. 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.

Easy access to appropriate 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.

> *"People are hidden and suffering often in silence – there is no support"*
>
> *(WASH sector humanitarian actor)*

> *"For people with the condition of spinal cord injury, the issue of incontinence is a huge survival issue"*
>
> *(Humanitarian disability sector actor)*

DEPRESSION AND GUILT ABOUT CAREGIVERS

Depression was another mental health problem, that was seen to be experienced by participants living with incontinence, which 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)

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.

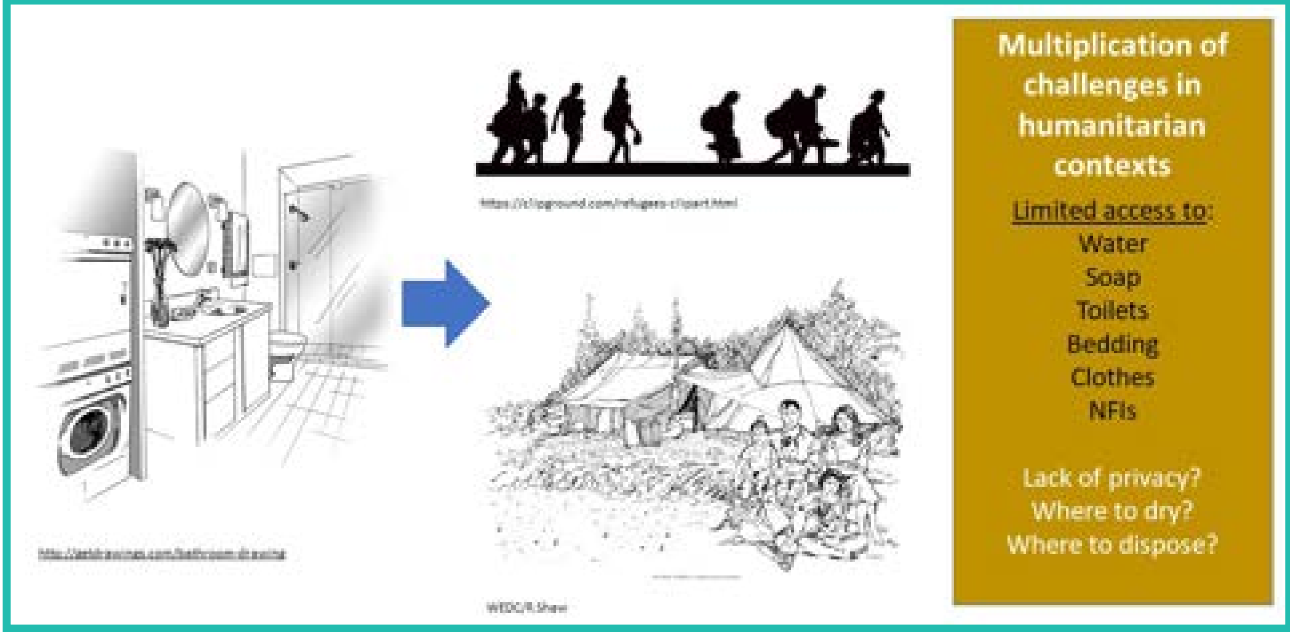
The true scope and scale of the problem is not known, largely due to the taboo surrounding incontinence, which makes planning for responses

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 Regional Syria 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.

Fig 3 - aims to challenge the readers of this report, to consider how difficult it would be to managing incontinence and having soiled clothes and bedding every day and night, when having access to water, a toilet, a shower and washing facilities. And then, to consider the additional challenges of managing it, if you are on the move, or are living in close conditions with others in collective centres or other humanitarian responses. The challenges are greatly multiplied.

FIG 3 - ADDITIONAL CHALLENGES OF MANAGING INCONTINENCE IN HUMANITARIAN CONTEXTS



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 4** 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, and see Section 3 in the main report - for further details.

FIG 4 - PEOPLE LIVING WITH INCONTINENCE IN HUMANITARIAN CONTEXTS AND IMPACTS OF NOT BEING SUPPORTED.

People who may be living with incontinence in humanitarian contexts

- Older people – including older people with dementia
- Children/ teenagers – wetting the bed due to traumatic experiences
- Women and girls – obstetric related - due to protracted or obstructed labour (including women and girls with FGM/C type III or IV)
- People with disabilities
- Women, girls, men and boys - facing serious sexual assault / rape / GBV
- Women going through the peri-menopause and menopause process (assume ages 40-60)
- People living with chronic health conditions – such as asthma, diabetes, epilepsy, or neurological, immune-system, or connective tissue disorders – or after operations, such as for prostrate cancer
- People with some mental health conditions or psychosocial disabilities – for example, people with learning disabilities, or people with alcohol or drug dependency

Contexts

- People on the move
- People who are displaced
- People in bomb shelters / basements
- People remaining in their own houses – such as on the frontline of a conflict or in a drought or cyclone situation
- People living in collective centres
- People living in IDP or refugee camps
- Displaced people living in host communities
- Vulnerable host community households
- People living in care homes (often older people or people with disabilities)
- Health facility users
- Pastoralist communities

Challenges to managing incontinence with dignity

- No privacy in shelter to manage incontinence
- Not having adequate access to clothes or bedding to allow washing / drying cycle
- No mattress protector, to prevent mattress soiling
- Inadequate access to materials to soak up urine or faeces – cloth, pads
- Not having adequate access to soap and water
- Insufficient access to sanitation facilities
- No-where to discretely wash and dry re-usable materials, clothes and bedding
- Nowhere to safely and discretely dispose of used incontinence pads
- May not know where to ask for support – either health or NFI-related
- Shyness to speak about their incontinence, or person hidden in shelter

Potential impacts

- Not able to live with dignity
- Health challenges from rashes (incontinence associated dermatitis. IAD) which can lead to serious infections
- Pressure sores which can lead to death
- Mental health challenges and suicide
- Domestic abuse and violence by caregivers
- Shaming or harassment by other community members
- Unable to leave house, attend school, join community activities, queue for toilets or to collect NFIs, or earn a livelihood

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 contexts[3]. 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 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 town[4].

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

(Credit: Bereket Seifu / NCA / 2021)

In DRC, the GBV, ASRH and WASH teams have supported work in a fistula hospital; and in Ukraine (2022), in partnership with HEKS-EPER, they are distributing NFIs. In Ethiopia (2020-2021), the team has been building on their MHM[5] 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 DanChurchAid (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 FGM.

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 was 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 3 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. Following not far behind, was also increased engagement by senior management and funding opportunities.

See **Section 4 in the main report** 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.

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

(Credit: NCA / 2021)

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.

(Photo: Mark Buttle, WASH Cluster Coordinator, Ukraine Crimea humanitarian response, 2016-2021)

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. The information included in this section, is expanded in **Sections 5 and 6 of the main report** - with more details and case studies.

Global humanitarian leadership, cluster, and cross-sectoral coordination

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.

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

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"

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.

General across all sectors

PROGRESS

A significant step forward, has been more specific inclusion of incontinence in the WASH chapter of the Sphere standards in 2018[6]. 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 action[7] and in 2021, the UNFPA ***Guiding principles for clinical management and program development - Obstetric Fistula & Other Forms of Female Genital Fistula,*** has been updated[8]. Protocols have also been developed by Humanity & Inclusion (HI) to support people living with spinal cord injury with self-catheterization[9]. 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 website[10], 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 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 5 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 5 - EXAMPLES OF PROGRESS ON INTEGRATING INCONTINENCE INTO HUMANITARIAN RESPONSES

EXAMPLES OF BARRIERS / GAPS TO GLOBAL ACTION
Limited commitment of Cluster leadership across sectors, globally and nationally & of organisational leadership on this issue
Limited prioritisation and clarity on requirements for action by donors
Lack of knowledge and confidence of humanitarian actors across sectors on how to respond
Feeling embarrassed to talk about this issue
Fear of causing offence and not knowing how to talk about this issue
Lack of practical guidance and tools for different actors – from doctors to community workers across sectors
Not enough funding
Not believing it is an important issue - as it is perceived as not life- threatening and not an emergency issue
Under prioritisation on rights to care and dignity and over-focus on numbers and medical interventions for life-saving only
Limited data on prevalence and under-valuing learning from the experiences of people living with this issue and quality of life

COUNTRY - examples	ORGANISATIONS ACTIVE - examples	HUMANITARIAN PROGRAMMING ACTIVITIES - examples
Syria/ Jordan/ Lebanon	Loving Humanity, NCA, HI, UNHCR	Distribution of disposable and reusable pads and other NFIs, UNHCR protection team active in Syria response
Iraq	NCA, MSF, HI	Distribution of WASH NFIs, advice on catheters, MHPSS support to parents on child bed-wetting
Greece	IRC, IFRC, NCA	Distribution of WASH NFIs, to people on the move, through hygiene kiosks in camps & using vouchers through health services
Honduras	IFRC	Phone line for parents of children wetting the bed to ask for assistance
South Sudan	NCA	Pilot of e-Voucher scheme for vulnerable households, with incontinence as a criteria
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
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.
Vanuatu	World Vision	Supporting older people and people with disabilities in accessing re-usable absorbent and cleaning products and local toilet chairs
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
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)

SUPPORTING ACTIONS ACROSS SECTORS
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)
Informal global email group across sectors since 2016 – >100 members - multiple sectors (2022)
Incontinence indicator in donor funding agreement (NCA – Norwegian Ministry of Foreign Affairs)
Organisational practical guidance for people with disabilities (HI and CBM) and collation of informal guidance (informal email group)
Innovation and supply focussing on incontinence NFIs for people with disabilities (UNICEF and WHO)
Production of reusable incontinence products (Loving Humanity, Jordan; World Vision, Mama Laef, Vanuatu)
Integration into wider trainings, such MHM & incontinence training (NCA) and OXFAM SaniTweaks training (OXFAM)
Publications and presentations / webinars (Global WASH Cluster & Sanitation Learning Hub)

PROGRESS

The WASH Cluster coordination team in Ukraine, provided leadership on the importance of supporting people with incontinence[11] 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 played a key role in getting incontinence talked about and to get it on the humanitarian agenda.

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.

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

(Credit: IRC / Greece / 2016)

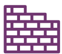
"We came across a house which had a pathway installed to a latrine for a young man in a wheel-chair... but the latrine was tiny, and the man clearly couldn't use it alone. His father also said that he has mental disability as well, so that he doesn't actually know when he needs the toilet, and regularly 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)

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 Syria response. Over 18,000 people with disabilities in the Syria 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.



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 studies[12], 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 Ghana[13], which has identified specific gaps.

> *"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)*

> ***"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 website[14] and chat options and an IWEG SRH Interagency Field Manual[15]. 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 prostrate, 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.

EXAMPLE SUGGESTIONS ON HOW THE HEALTH SECTOR COULD IMPROVE THE SUPPORT THEY PROVIDE FOR PEOPLE WITH INCONTINENCE:

- Increase capacity and confidence building for health staff on how to talk about and support people with incontinence.
- Include questions on incontinence in nurses' assessment questionnaires for patients' arriving at the health facility.
- Make sure that all mattresses and beds are waterproof, or always have waterproof covers.
- Increase privacy for toileting in the facility.
- Ensure that incontinence pads are available in the health facility.

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. 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.

> ***"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)*

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 Hospitaller 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 Malawi[16]. 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)*

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 & 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 disabilities[17].

HELPAGE AND PARTNERS UNDERTOOK AN ASSESSMENT OF 1,335 OLDER PEOPLE IN COX'S BAZAR CAMPS (2018)[18]

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.

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

(Credit: M. Farrington/OXFAM/2021)

GAPS/BARRIERS

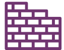
People with disabilities and older people and their needs are still often overlooked in humanitarian contexts, across all sectors. Older people living alone, or as an older person couple, may face particular challenges in managing their incontinence and in particular in relation to accessing appropriate 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.

> *"Older people are mostly invisible to us"*
>
> *(Humanitarian health sector actor)*

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 context[19].



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 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.

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 Sphere[20]. 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 kits[21]. The Absorbent Products TAP training is online (see box) 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.

The box also provides links to another open training, developed by NCA on MHM and incontinence, focusing on the work of the WASH sector.

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

WHO training in absorbent products for incontinence

A series of mass open online courses (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.gate-tap.org/

NCA on-line training on MHM and incontinence

NCA has developed an online training on MHM and incontinence, which is available online to any interested participants. This can be accessed through:

https://fabo.org/nca/NCAWebinarSeriesMHM

In addition, Loving Humanity in Jordan and other locations and World Vision with Mama Laef in Vanuatu, have been developing re-usable incontinence products and tools. See box below and **Fig 6** – which provides an example of one of the awareness-raising posters, prepared by World Vision and partners, in Vanuatu.

VIDEOS OF WORK BEING UNDERTAKEN SUPPORTING PEOPLE LIVING WITH INCONTINENCE

Loving Humanity

The work of Loving Humanity and two videos of the incontinence-related washable products and babies' nappies, made for people affected by humanitarian emergencies, can be seen through these links

www.lovinghumanity.org.uk; https://drive.google.com/drive/folders/1hXRYlim8qB0SUotkv1hKoZftTQTzy661?usp=sharing

World Vision, Vanuatu

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

FIG 6 - 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 7.**

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

RECOMMENDATIONS FOR NCA

Commitment of NCA senior management 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 NMFA and NORAD agreements. The overview recommendations for NCA are as follows:

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

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

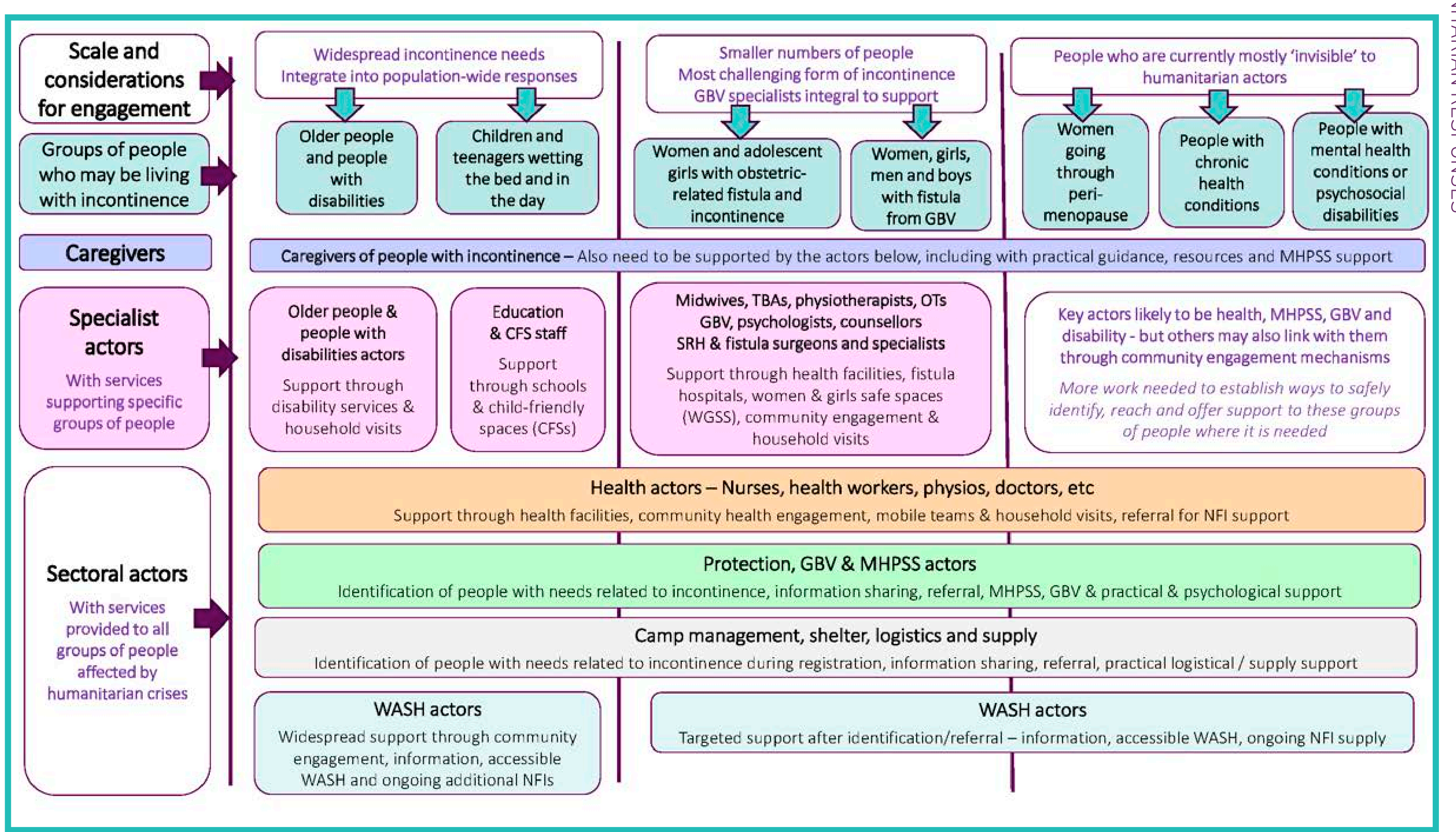
NCA-R3 - Strengthen coordination, planning, baselines and programmes

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 7 - 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, while recommendations 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 of the main report.** They are supported with additional, more specific practical recommendations, supporting the implementation of the overall recommendations.

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

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 main report for more details, learning, explanations, case studies and guidance for the ways forward.

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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.

ENDNOTES

1 Credit for line image of family in a camp: Shaw, R, WEDC, Loughborough University

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SAVE LIVES AND SEEK JUSTICE

Norwegian Church Aid works to save lives and seek justice. Our support is provided unconditionally with no intention of influencing anyone's religious affiliation.

Norwegian Church Aid is a member of the ACT Alliance, one of the world's largest humanitarian coalitions. Together, we work throughout the world to create positive and sustainable change.

To save lives and seek justice is, for us, faith in action.

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