

Mapping of Support for People Living with Incontinence in Humanitarian Contexts; Through the lens of WASH, Gender-Based-Violence (GBV) and Adolescent Sexual and Reproductive Health (ASRH)

NCA are delighted to share the outputs of a mapping process, undertaken July - December 2022. This mapping is the first of its kind globally, focusing on support for people living with incontinence in humanitarian contexts. It is a foundational study, which has found a range of action across agencies, sectors and contexts, as well as multiple gaps and challenges.

Key outputs of the mapping process

- 1. Main report
- 2. Summary report
- 3. Supporting document 1 Longer case studies
- 4. Supporting document 2 Practical resources

These and other outputs will be available through the NCA website (outputs to be added soon, on this page) - https://www.kirkensnodhjelp.no/en/wash

"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".

(WASH sector humanitarian actor)

Objectives

The objectives of this mapping process were to map how NCA and humanitarian actors globally, are currently engaging with and supporting people living with incontinence in their humanitarian responses. It also aimed to provide guidance on how NCA can strengthen the integration of incontinence in its own humanitarian responses and to encourage other actors to increase their engagement at scale.

Why incontinence is important

Incontinence 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 their physical and mental health and their caregivers. It can also

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

(Humanitarian disability sector actor)

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. In humanitarian contexts, access to WASH facilities is often difficult and challenges in managing this distressing condition, are greatly multiplied. See Fig 1.

Methods and focus

The mapping was led by the NCA WASH team, with support from the GBV and ASRH teams. The process included a webinar, an online survey (18 NCA staff); and a desk study. 52 actors from NCA and other global humanitarian actors were also interviewed in key informant interviews or focus group discussions. Respondents were from 23 agencies and are currently working in implementation in 13 countries, or at global level in supporting roles. The main focus of the process was on WASH, along with Gender-Based Violence (GBV); and Adolescent Sexual and Reproductive Health (ASRH). But the process also considered the responsibilities across other sectors, including: Health, Mental Health and Psychosocial Support (MHPSS), Protection, Disability, Logistics, Supply and Camp Management.

Fig 1 – 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 perimenopause and menopause process (assume ages 40-60)

People living with chronic health conditions – such as asthma, diabetes, epilepsy, or neurological, immunesystem, 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



Results/conclusions

Progress has been made across agencies and humanitarian contexts. NCA started providing support on incontinence in humanitarian contexts in Liberia in 2012 and Lebanon in 2014, and have continued this work in a range of countries, such as in Iraq, Ethiopia, Greece, South Sudan, DRC and Ukraine.

Respondents across agencies, highlighted a range of locations in which some efforts have already been made to support people living with incontinence, such as people: on the move; in bomb shelters; in collective centres; in care homes; in IDP or refugee camps; in health facilities; and in challenging locations, where access is difficult. Examples of action were shared from: Liberia; Tanzania; the Regional Syria Response; Iraq; Greece; Honduras; Somalia; DRC; Ethiopia; South Sudan; Ukraine; East Asia; Vanuatu, and Algeria.

The mapping also identified a few examples of support provided at scale, particularly related to children who have been traumatized and have started wetting and efforts have increasingly been made to support people with disabilities, particularly people living with spinal cord injury. Large-scale support has also been provided for older people in Ukraine, following pro-active leadership by the WASH Cluster Coordinator, started during the Crimea response.

Responsibilities for supporting people with incontinence, clearly cut across professions and sectors. See Fig 2. Yet, it is also very clear that this remains an overlooked issue by most agencies and sectors, with most implementation only happening at small-scale.

Recommendations

Three sets of practical recommendations have been made:

- 1. Ten overview recommendations
- 2. Recommendations for NCA, for strengthening its own humanitarian programming
- 3. Recommendations for wider global humanitarian actors split by sector and actor groups

These focus on the need for increased leadership by IASC and across all key sectors, identification of responsibilities by sector and increased awareness-raising and capacity building for different levels of actors. Donors and UN agencies need to specify their requirements for action in the area of incontinence; and basic standards, tools and guidance are needed to support implementation agencies in their work. A range of practical recommendations have also been made by sector. Underlying all of these efforts, there is a need to increase engagement with, and to seek the opinions of, people who live with this condition in humanitarian contexts, on what they need to live their lives healthily, with improved mental health and dignity.

Contact for more information

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Examples of case studies:

- People with disabilities HI and World Vision
- WASH supporting children wetting the bed – IRC and IFRC
- Coordination in Ukraine by Ukraine WASH Cluster
- Older people and people with disabilities in Ukraine – NRC, Age and Disability Working Group/HelpAge, Polish Government, HEKS-EPR/NCA, HI, RedR, Oxfam
- Integrating incontinence into health sector responses – MSF
- Fistula UNFPA, MSF & partners
- Responding to violence Nairobi Women's Hospital
- Integrating incontinence into cash e-Voucher scheme - NCA South Sudan
- Learning from MHM NCA Ethiopia
- Washable products across contexts – Loving Humanity
- Protection support at scale in Syria – UNHCR
- Supply and innovation UNICEF and WHO

Fig 2 – Overview on key sectoral responsibilities in providing support for incontinence in humanitarian response

