Mapping of support for people living with incontinence in humanitarian contexts

Through the lens of WASH, GBV and ASRH

SUPPORTING DOCUMENT 1

LONGER CASE STUDIES

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Introduction

Supporting document 1 documents a series of case studies, where NCA and its partners, or other global humanitarian actors, have undertaken specific incontinence-related actions in humanitarian responses, or where they have been involved in learning with relevance to implementation. Some are examples from specific humanitarian responses, and others (titled as 'global') cover responses across a number of country contexts.

These case studies have also been referred to in the summary and main reports, but the case studies in **Supporting Document 1** - provide further details. It is hoped that these longer case studies, will be of particular use to implementing agencies, working on the ground in humanitarian contexts, as they work out how to improve their humanitarian responses, to strengthen the support they provide to people living with incontinence.

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** – Dec 2022
- **Main report** – Dec 2022
- **Supporting document 1** – Longer case studies
- **Supporting document 2** – Practical resources

Acknowledgements

Participants to the mapping process, from NCA and 22 other agencies, including participants of the online survey, KIIs and FGDs, are currently based in, and working on humanitarian responses and associated programmes in 13 countries and shared experiences from working in a range of other country contexts. Examples were shared from countries in Africa, Asia, the Middle East, Europe, Central America and the South Pacific.

This document has been prepared under the Strategic Partnership Agreement between NCA and the Norwegian Ministry of Foreign Affairs. The work has been 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 supported by independent consultants – Dr Sarah House and Dr Chris Chatterton.

Please see the summary and main reports, for a full set of acknowledgements for people who contributed to this process.

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*, *Supporting document 1 – Longer case studies,* Norwegian Church Aid

Case studies

Section 1 – Humanitarian response case studies

Section 2 – Global humanitarian actors - Humanitarian response case studies

Section 1

NCA – Humanitarian response case studies

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CS-NCA-A – 2014 – Syria and Lebanon –NFIs for older people

Focus	**Non-food items for older people with incontinence**
Location	**Syria – across all governorates** **Lebanon – North (Akkar) and in Bekaa camps hosting Syrian refugees**
Dates	Dates incontinence-related work in Syria and Lebanon: 2014-2022
Context	<u>Syria and Lebanon:</u> • NCA mainly works through local partners for WASH in Syria and Lebanon. Hygiene practices are generally good, with most people having a high awareness and knowledge on how to prevent diarrheal diseases. However, living in displacement situations, whether it be in camps, unfinished buildings, or in informal settlements, with poor access to water and sanitation and lack of basic hygiene items, makes practicing good hygiene practices a challenge. A huge amount of rehabilitation work is needed, including for water and sanitation infrastructure, as the systems have been severely damaged by the war (in Syria), and the high number of users in hosting communities, also contributes to the systems break down, which increases the need for maintenance. Most water sources (wells), are also pumped and run by diesel generators. The current fuel crisis in the region, means that water is pumped less regularly, which also leads to decreasing access to water for most people in both Lebanon and Syria. In addition, changes due to climate change, such as impacts on drought and flooding, also impact on access to water and also means that sewage systems overflow and this impacts public health. Recently, there has also been a cholera outbreak in Syria and Lebanon. • In Syria, NCA has undertaken a lot of rehabilitation of wells and water and sanitation systems, including network repairs, and NCA has been a pioneering agency, in installing projects for solar pumping, installing several solar systems for wells across Syria, ensuring safe and “green” water, to thousands of people in need. They are also working on solid waste disposal, as there is a lack of solid waste management services. • NCA has also been rehabilitating WASH facilities in schools and clinics, including solar panels, and working to make them more suitable and friendly for people with disabilities. In the hygiene promotion programme in schools, which is implemented mainly through health clubs, MHM is a topic being addressed for both girls and young women. • The hygiene promotion activities being undertaken in Syria, are currently focusing on Covid-19 and MHM-awareness. Sessions held so far, have been run for survivors of GBV and in communities more widely.

	• Mostly people use normal cloth to manage their incontinence. Older people know how to use them for children, so they also use them for themselves.
Activities	• Some distribution of incontinence-related hygiene items, were provided through dignity kits, before 2021, although specific standards for the distributions were not followed. This specific dignity kit consisted of an additional package added on to the standard household package, and the hygiene promotion staff member, was responsible for making decisions on whether it was needed or otherwise. • In 2022, the NCA partners undertook post-distribution monitoring (PDM), which included recommendations to improve the hygiene kits. Some responses received, indicated that older people still needed more support.
Successes	• The repair of water and sanitation facilities, including with sustainable power sources, and provision of hygiene information and kits, will have contributed to helping people to manage their incontinence. • The distribution of incontinence pads/diapers, soap and other items, have been provided to older people, in camps in the Syria and Lebanon response.
Challenges	• Whether actions occur on the ground, is influenced by the interest of the team in each programme, as currently the support on incontinence is not yet systematized. • In Syria, there are also problems with increased prices, linked to the hyperinflation in the country. This poses a problem with the provision of NFIs, due to their high cost.
Opportunities for the future	• The GBV team in the Syria programme, provides support for people affected by GBV and they are referred for medical assistance. Access to people affected by GBV through this support, may also provide opportunities for sharing information and providing support on incontinence. • People who suffer from incontinence, have started to answer questions in FGDs and in-depth interviews (IDIs). They have also started talking to the teams during distributions and there are expectations for support. These routes to communication and engagement, offer opportunities to learn about what is needed and to ask questions. The team undertaking the distributions, need to be trained how to ask these questions sensitively, to make the most of these opportunities, in a sensitive way. • Opportunities from post-distribution monitoring (PDM) processes, including through engagement in FGDs, are also important to reflect on and offer the opportunity to modify responses, as we ask what items would you like and what was missing etc. • It would be useful to make incontinence a standard section of the WASH assessment tools

CS-NCA-B – 2015 – Iraq – Discussions with older people on NFI incontinence distributions

Focus	**Supporting older people with NFIs for incontinence**
Location	**Iraq, Nineveh province and Dohuk governorate, mainly in IDP camps**
Dates	Dates incontinence-related work was undertaken in Iraq humanitarian response: 2015-2019
Context	• The early days of the Iraq response focused on IDPs, Yezidis, living in IDP camps in Dohuk governorate. It was a classical camp WASH response, with a strong hygiene promotion component. Later on, the response also covered IDPs from Mosul, after the end of the Islamic State in Iraq, in 2017. Since 2016, NCA also started its GBV programme in Iraq, firstly focusing on survivors of GBV, who had escaped, or who had been released from the captivity of the Islamic State. In Iraq, NCA was self-implementing its programmes. • The WASH-related activities in the NCA Iraq response, focused on ensuring that IDPs in camps had access to safe water and toilets, which meant establishing, operating and maintaining water and sanitation systems. 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 material, including sanitary pads and later, adult diapers. • In Iraq, the issue of incontinence, was talked about openly, as the hygiene promotion programme, was more established. The HP teams, were part of the camp population, and had trust and respect among community members. They saw how the older people in their communities and others suffered and struggled with the consequences of incontinence.
Activities	• The teams started distributing some diapers and extra soap for older people. But at this stage, this was not undertaken in a systematic way and no formal trial was undertaken to check suitability of the response. But the team was listening to the needs of people living with it, to better understand their needs.
Successes	• The distribution of incontinence pads/diapers, soap and other items to older people in camps in Iraq. Initially in Iraq, older people used sanitary pads to manage their incontinence. However, after consultation with the older community members and NCA hygiene promoters, special adult diapers were distributed, or made available to older people. These were distributed to specific households, upon community identification, through HP community focal points.

	• The initial NCA work on supporting older people with their incontinence, including the work in Iraq, led to increased discussions and action within NCA as an organisation. This was also the trigger, that led to the first discussion on incontinence in humanitarian contexts, across agencies and across sectors, in 2016. This later led to the formation of the global email group on incontinence.  **Distribution of incontinence pads to older people in the Mosul, Iraq response, 2015** (Credit: NCA / 2021)
Challenges	• Whether actions occur on the ground, is influenced by the interest of the team in each programme, as currently the support on incontinence is not yet systematized.
Opportunities for the future	• Opportunities from post-distribution monitoring (PDM), using FGDs are important. These provide opportunities to reflect on, and modify responses, if asking questions, such as what would be the preferred items, what was missing etc. • The lessons from this experience, also highlight the need to make incontinence a standard section of WASH assessment tools, in order to systematize the process.

CS-NCA-C – 2016 – Greece – WASH response to the Europe refugee crisis

Focus	**WASH response to the Europe refugee crisis**
Location	**Athens – various camps and sites for refugees**
Dates	2016 – 2017
Context	• The European refugee crisis came into full force in 2015, with more than 800,000 refugees and migrants crossing the Aegean Sea from Turkey to arrive in Greece. The vast majority transited through Greece en route to European countries further west. That began to change in late November 2015, when the Former Yugoslav Republic of Macedonia began restricting border passage to certain nationalities. In early March 2016, the border closed entirely, effectively stranding tens of thousands of refugees in Greece. In April 2016, at the start of the response, there were an estimated 46,000 refugees and migrants living in Greece, unable to leave the country by legal means. • This project was initiated in response to needs and gaps in the two sectors: Food and Water, Sanitation and Hygiene (WASH).
Activities	• Operation of sanitation systems (desludging) and some construction of sanitation facilities. • Operation and maintenance of water systems. • Hygiene promotion awareness, including provision of hygiene material. The hygiene material, included diapers for adults, supplied in response to needs. • Needs assessments were undertaken, including questions on both MHM and incontinence.
Successes	• Including incontinence in the initial assessments for WASH needs. • Undertaking distributions of incontinence items (adult diapers), to targeted families.
Challenges	• The response was not so well organized and the sites where refugees were living, were constantly changing. Also, what humanitarian actors were allowed to do, also varied from week-to-week. Firstly, it was not permitted to construct any permanent, or semi-permanent structures. This limited the WASH services in what it was possible to deliver and the quality of services. Then, the next week, humanitarian actors, would be asked to do semi-permanent structures. Also, 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. No-one wanted to be in Greece. They all wanted to leave for another European country, meaning the soft components of WASH were difficult, as people

	were always ready to move on, or leave to another place. It also means, 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 already left, or had been moved by the authorities.
Opportunities for the future	• Having incontinence as part of WASH assessments, even rapid ones

CS-NCA-D – 2020 – Ethiopia – Learning from MHM and disability for incontinence

Focus	**Learning from MHM and people with disabilities for support for incontinence**
Location	**Jewi Refugee Camp and Gambella Town, Gambella Regional State, Ethiopia**
Dates	NCA has been working with South Sudanese refugees since 2014. They initially worked in Leitchor, where the refugees currently in Jewi, were first residing and then later in Jewi refugee camps. They moved here in 2015, following flooding. In 2019, the NCA also started a GBV and child marriage-project in the host community and in 2020, the WASH programme also started working with the host community. The MHM pilot was run between July 2020 to March 2021.
Context	• The current numbers of refugees in the Gambella region are 373,925 (73,768 households) and in Jewi camp, 70,394 refugees (11,591 households) (data from: UNHCR, 30 September 2022) • Currently there are 7 camps in the Gambella Region. Jewi camp is supported by NCA, one camp is supported by OXFAM and another camp is supported by HelpAge. Two of the camps are 110 km away from Gambella Town. • The WASH team have been using the Community-led Total Sanitation (CLTS) approach, to address the communities' toilet and hygiene needs. This has had some success in communities supporting themselves in toilet construction. But currently only 26% of households have a toilet, as some from the emergency period, have fallen down. • It is a very difficult period, because NGOs and donors have stopped supporting priority areas and the food ration has recently been cut to 50% of its previous level. Some households are now selling items, such as the corrugated sheets from their houses, or selling blankets, or WASH products, to pay for food. The host community has income from different sources and some NGOs have now started supporting livelihood projects.
Activities	<u>Establishment of small enterprises for MHM:</u> • Previously menstrual kits with both disposable, and in some cases, reusable pads, were distributed to the refugees, but this only happened when they were in stock. So, MHM gaps were discussed regularly in coordination meetings. Only a few NGOs have been supporting women and girls with MHM, or dignity kits.

	• The NCA team supported a piloting of the establishment of enterprises, involving women and girls, to make reusable pads and to distribute them at double the cost of making them. They also supported schools and safe spaces with female-friendly-latrines. • These efforts, raised the profile of MHM issues with donors and the government, as the enterprises were producing the pads at affordable prices in the camp and host town. • Initially, they legally established one enterprise in Jewi camp, to produce the pads and supported them to establish a bank account. NCA also gave them sewing machines and raw materials. • Today there are 15 members of small businesses in the camp and 15 members in the host town (two business groups having a total of 30 members). The pilot ran for one year until the end of March 2021. • The progress has been amazing, and they have become the biggest supplier in the area, with some UN and other NGOs purchasing some of their products. • They still need support and regular follow-up, and there is an intention to identify additional raw resources to support them and to continue to create market linkages with potential buyers. • The team documented their work on MHM, in a publication: Dagne, B and Seifu, B (2021) *Menstrual Hygiene Management: Inclusive MHM in Gambella, Ethiopia*, August 2021, WASH Learning Series #2, NCA <u>People with disabilities and learning on incontinence:</u> • 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 were found to be lacking 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 higher costs and poor hygiene can lead to complications for them. *"A mother in one FGD, mentioned that some of her family members face mobility challenges and they have incontinence and asked if there is any way we can support them?"* • It was learnt that when they do not have money, they try to use different clothes and their own underwear, to manage their incontinence and to enable them to be able to visit for distributions from NGOs. <u>Incontinence – IOM/Innovation Norway – assessment of needs for material products:</u> • The International Organization for Migration (IOM) 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. They are aiming to learn about products for the management of faeces for children less than 5 years old, as well as incontinence products for adults. This will be followed by a market dialogue, to provide ideas on possible solutions. This is while seeking to foster a humanitarian-private sector partnership, to come up with a viable solution, and then to run a test of this solution, through a pilot in Ethiopia.

- IOM were looking for partners who have experience in the production of MHM products in Ethiopia, to learn for incontinence. Hence, they contacted NCA.

Re-usable MHM dignity kits made by a small enterprise team in Jewi Camp, Gambella

(Credit: Bekalu Dagne Agize/NCA/2021)

- The NCA Gambella team, were contracted to support the initial assessment process, to learn about the needs for products for babies' nappies and adult incontinence products (diapers). They developed research questions and contracted a consultant to work on the assessment for 2 to 3 months, and oversaw and supported the process. They are in the process of report writing from this assessment.
- They planned to work with the Regional Health Bureau and also aimed to visit a fistula hospital in Ethiopia, to see what they can learn from their experience.

Successes	• The establishment of local MHM enterprises in both a refugee camp and the host town, has offered opportunities for income-generation and for the refugees and host communities to access reusable products. • The learning from the MHM enterprise development and the assessments with people with disabilities, has also offered opportunities for learning, to develop solutions for incontinence. • It is very positive that the IOM/Innovation Norway project is looking to test and establish manufacturing of baby nappies and adult incontinence products in Ethiopia and that it is involving the NCA team, utilizing their experience of supporting the enterprises for MHM.
Challenges	• A lesson from MHM, is that in addition to products, sanitation and bathing facilities are also needed near to the shelter, to enable women and girls to be able to manage this effectively. Many households do not have access to these facilities in the Gambella context, so this poses challenges for people with incontinence. • The reduction in aid, also means that households are prioritising finding funds for food and other basic needs, so they may be selling hygiene items for this purpose.
Opportunities for the future	• The NCA GBV team already works to support women, girls and children, through safe spaces and working to prevent child rape. These could be one entry point to also talk about incontinence, and links might be possible through schools. • For adolescent girls, discussions on early marriage and child marriage, have already been linked in discussions with WASH and MHM, so this kind of linkage, could also be considered to provide information and support on incontinence.

CS-NCA-E – 2021 – South Sudan – Cash e-Vouchers for incontinence

Focus	**Pilot for e-Voucher cash support including people with incontinence**
Location	**Gumuruk IDP camp and Gumuruk Town, Jonglei State, South Sudan**
Dates	Overall pilot – June to December 2021; distributions between November to December 2021
Context	In cash distribution schemes, cash and vouchers often go together. Usually, two kinds of distribution are undertaken: e-vouchers to distribute cash, and in-kind distributions, where NFIs are distributed directly, which is usually used in very remote areas, which may not have a market. Gumuruk camp is a camp hosting South Sudanese IDPs. It is an area affected by conflicts, where people have already been settled for a while and where there is a small market. NCA was already implementing a cash programme for WASH products in Gumruk camp, so they decided to undertake a pilot to support for people with particular vulnerabilities, including considering households, who have members who are living with incontinence.
Activities	The NCA team in South Sudan, established a pilot e-Voucher cash transfer scheme, to support 232 vulnerable households in Gumuruk camp and 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.  **Registration process for e-Voucher beneficiaries, South Sudan** (Credit: Bereket Seifu/NCA/2021)

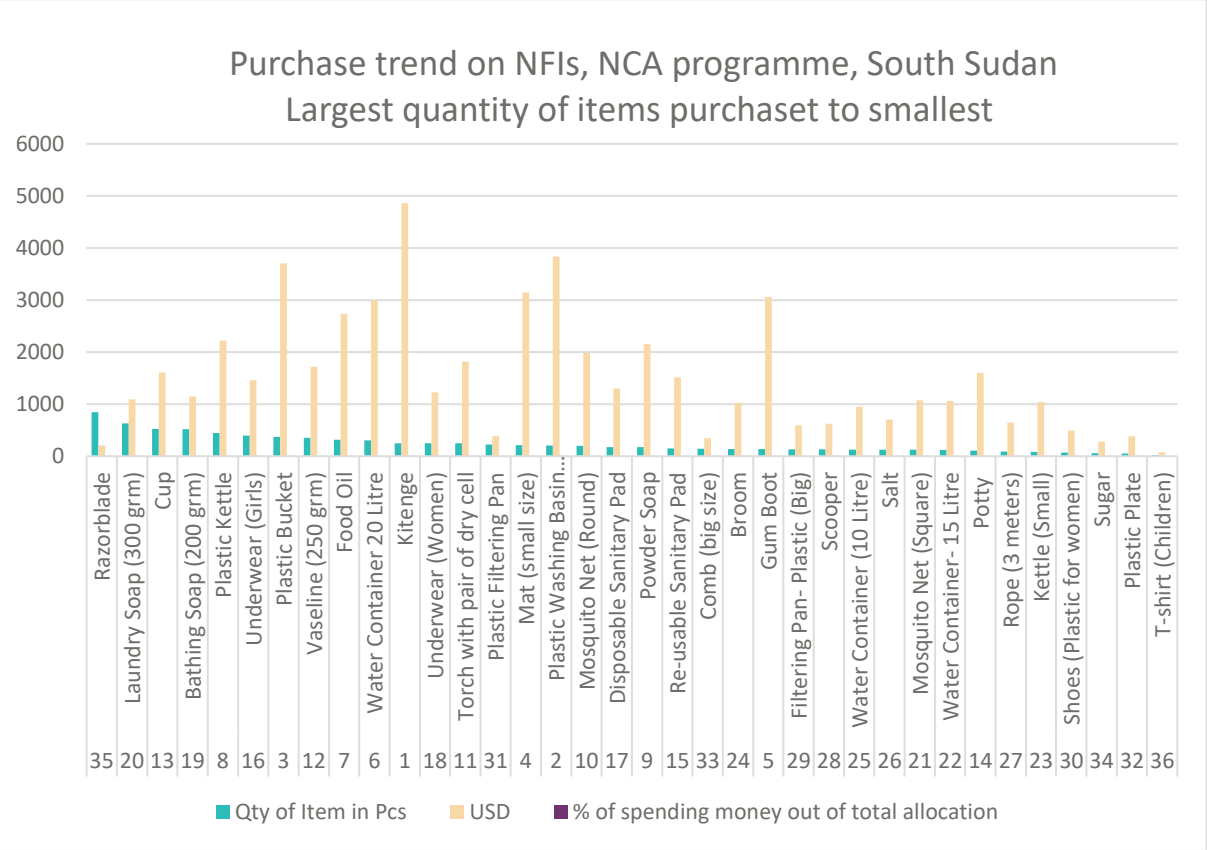
	The following key activities were included in this pilot. <u>Initial steps in establishing the pilot and providing support:</u> 1. Selection criteria were developed, to identify the most vulnerable households, which was then inserted into a scoring system, to rank the most vulnerable households. The criteria included scores for – households which have the following characteristics, or people within them – female-headed, big family size, children under 5, people with disabilities, people with HIV, girls and women in reproductive age, people with incontinence and older people. The criteria were developed and agreed by NCA, funding partner(s), the local government and the community leadership. 2. A training was undertaken for enumerators, using the Kobo toolbox, and they then undertook a registration of all households in the camp and town, including the criteria as part of the registration process. 3. Efforts were also made to identify people living with incontinence, through FGDs and KIIs and the gathering of secondary data. 4. Initial in-kind support, was given to people arriving at the town/settlement – with materials for women and girls of menstruating age and double this for people living with incontinence. 5. They found through the assessment and registration process, that most people don't have purchasing power, so other household items may be sold to buy priority items. <u>Cash transfer to the most vulnerable households:</u> 6. The households identified as particularly vulnerable (1% of households in the communities), received an e-Voucher transfer in two wallets – one for money for food (aiming to prevent the selling of the hygiene items to buy food) and the other for the additional hygiene items. Only the households ranked as most vulnerable over-all, received this additional support. So, some households which have people living with incontinence, or people with disabilities, would still not have received any additional support. 7. The households with people with incontinence received an extra USD 80 in the hygiene wallet, for the first month and USD 21 for the second two months. This was the same amount that was allocated to females or reproductive age. 8. People with incontinence can 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), and underwear (but the vouchers only covered costs for underwear for women or girls, male would need self-purchase) or sanitary pads (to be used instead of incontinence pads), or a potty for children.

	<u>Memorandum of Understandings (MoUs) with vendors and monitoring of sales:</u> 9. MoU contracts were set up with 6 vendors[1], which included the conditions, obligations of vendors and the NCA and a list of items, that can be purchased with the vouchers and the maximum price they can be sold at. They cannot charge more for the specified items, but they can compete with the other vendors to charge less. 10. Each vendor was trained and also provided with a SMART phone to use during market hours, which are collected at the end of each working day. 11. The dashboard presented the items over time in real-time on the mother platform (RedRose), to follow the sales and to establish what the beneficiaries are prioritising and buying. This is also linked to the characteristics of different beneficiaries, which offered opportunities to establish priorities for particular groups of people. 12. The monitoring module, also included the set of items in each basket and the shop keepers can also see what items have been sold direct from the platform. But it cannot identify if all items have been sold, or problems with the items. NCA provided the vendors with a print-out of the sales report each day. 13. The graph (see below), shows the items sold over the period 01 Nov to 31 Dec 2021 (3 months payments, paid within a 2-month period). This indicated both the quantity (piece/packet) and the overall cost for total number of items purchased.
Successes	This process 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 that the beneficiaries can go to the market and buy what they need, even when the teams cannot reach the people directly.
Challenges	• Identification of people with incontinence was challenging due to taboos and people being hidden by their families. • People are in dire straits, as they have very little access to resources and food – they often prioritize clothes, shelter and food before other items. • People sometimes have different priorities, such as for purchasing clothes. This is because most of the people were returnees coming back to their settlements, and they had lost everything, as they fled to save their lives. They also tend to prioritize food and shelter needs, as they are in dire straits. So, they sometimes buy soap using the e-Voucher from the market and then sell it to buy other items.

[1] NCA (2021) Memorandum of Understanding for NFI e-Voucher cash transfer scheme

	• The e-Voucher system, is not a long-term solution, with external funds to support it. • Since the cash voucher distributions, it has also not been possible to undertake post-distribution monitoring (PDMs), or to expand the programme, because of communal fighting and insecurity, impacting access. • There is also a gap in the knowledge on incontinence, of WASH and health workers.

Fig 1 - Spending on and quantity of NFI items – e-Voucher cash transfer scheme (from three months payments, paid in 2 months)



Opportunities for the future	• There are opportunities to expand and roll-out the e-Voucher system as part of the on-going programme. • There are opportunities to link the WASH activities with the GBV and ASRH teams in South Sudan, which work in both development and humanitarian contexts. The GBV team, works on both prevention and response, in communities, considering WASH services and supporting health clinics. • Some community workers, work on both WASH and GBV. There are already plans for the WASH and GBV, to work together in the Upper Nile State.

CS-NCA-F – 2022 – DRC – Opportunities for WASH, GBV, ASRH engagement

Focus	**Opportunities for strengthening WASH, GBV, ASRH engagement in incontinence**
Location	**North Kivu, Eastern Democratic Republic of Congo (DRC)**
Dates	GBV programme started 1994, the WASH programme (2008), and ASRH 2020
Context	Incontinence is known to be a consequence of sexual violence, including for young adolescents giving birth in North Kivu, DRC. There are people who need to be referred, 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. Fistula is a very sensitive issue and is a big problem, particularly for the social life of the person affected by it, as they cannot sit with others and are isolated. If the fistula operation is successful, then social integration, is not such a problem and the person is more accepted. Many people with fistula are hidden and not found.
Activities	<u>The WASH programme works on:</u> • Water access with networks and boreholes, emergency latrines and also latrines in schools and health centres and communication for hygiene behaviour change. They also work on MHM in camps and communities. This is through promotion and community consultation, making sure that girls and women feel safe using the WASH and they are also given dignity kits, including disposable and reusable pads and buckets and soap. • The NCA WASH programme has indicators for MHM (NMFA SPA Output 3.4) and for incontinence and hence NCA in DRC is asking the partners to report against these indicators. <u>The DRC GBV team works in both humanitarian and longer-term programmes:</u> • 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 also work in health structures, including a fistula hospital (see below) – training the health workers and providing medicine to these structures. Plus, they also work with women and girls in safe structures and provide economic support to survivors of GBV.

	<u>The DRC ASRH programme started in 2020 and links adolescents into the GBV programme:</u> • The ASRH programme focusses on SRH education and working with youth groups, and the NCA ASRH programme also works on skills training and with parents in groups, as well as training nurses, with information about adolescents and their needs.
Successes	**Existing engagement in the Panzi referral hospital in Bukavu, where fistula care is given –** • The NCA GBV and ASRH team, has been working with the Panzi fistula hospital in 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 living with incontinence themselves. • WASH have been supporting WASH facilities and water network in the hospital. Women with fistula need easy access to latrines, more than others and to showers. So NCA works to support, to ensure that there are enough water and clean latrines available for the women and girls' needs.
Challenges	• In IDP contexts, people don't know what the term incontinence means. It is also culturally sensitive, so people will not openly talk about it, even though many people have it. • It is also a new topic in humanitarian work, and there is not much information in terms of guidance or standards. Hence, it is a big challenge, as everyone, including at Provincial Coordinator level, actors do not know much about it. • Although the WASH programme has an indicator on incontinence and they are asking partners to report on it, this subject is not well known, by the WASH programme partners, so the team try to explain to them.
Opportunities for the future	• Training would be needed for the NCA teams and partners, and then this can be integrated into existing aspects of NCAs work across sectors. The programme has already been looking at where they can integrate and coordinate across the three sectors – WASH, GBV and ASRH • 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 this subject in new modules, into the existing health workers 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.

	• In safe spaces for women, the programme could do awareness-raising on incontinence. • All three teams have good opportunities, to discuss this subject with different groups in the community and work with them. They also have good opportunities to also help their partners get in touch with people who have incontinence, who stay home, so they can encourage them to be referred to the hospital. • WASH could help when people are identified with incontinence, through the GBV/ASRH activities. They could include incontinence in hygiene management and MHM activities. The MHM learning also offers learning for incontinence.

Fistula hospitals in Eastern DRC –

Information on three of the hospitals in Eastern DRC, which undertake fistula surgeries (extracted from the webpages indicated):

- **The General Referral Hospital of Panzi is located in Bukavu, the capital of South Kivu** – The Medical Director is Dr Denis Mukwega. He founded the hospital in 1999. Despite numerous setbacks during the wars, it has grown to a 334-bed faith-based hospital, that offers a diverse array of medical and surgical services. More than 70% of Panzi patients are survivors of sexual violence. Given the facility's expertise in repairing fistula, patients now come to Panzi from all over the Kivu provinces in Eastern Congo and beyond. https://www.hopitaldepanzi.com/
- **Imagerie des Grands Lacs, is in the remote city of Beni in North Kivu province** – It is a private, non-profit facility. The facility has 10 beds dedicated to fistula patients and serves a catchment population of 1.5 million, most of who are dispersed throughout the surrounding rural area, where demand for fistula repair services is extremely high. The hospital has one fistula surgeon and receives funding from Fistula Care, to provide 108 fistula repairs a year.
- **HEAL Africa Hospital is a faith-based hospital in the North Kivu capital, Goma** – HEAL Africa, began as a small surgical training clinic in 1996, and over time it has expanded its services to become a 180-bed hospital that performs more than 280 fistula surgeries per year. Local volunteers help to identify patients and bring them to the hospital. At any given time, between 120 and 160 women, are waiting for fistula repair at the hospital. HEAL Africa also works with village and religious leaders to develop plans to care for the area's vulnerable populations. https://healafrica.org/our-story/

CS-NCA-G – 2022 – HEKS-EPER – Ukraine – Non-WASH actors working on incontinence

Focus	**Learning on the information needs of non-WASH actors working on WASH for incontinence**
Location	**South and Eastern areas of Ukraine**
Dates	2022
Context	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 living there. Not many agencies are working in these locations, due to the level of insecurity. Mainly older people are left behind, as young and middle aged-people are more able and hence more able to leave. Some older people can't move and some don't want to leave.
Activities	The programme works on the provision of food and WASH NFIs and also provide some mental health and psychosocial support (MHPSS). 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 of 2,000 people with incontinence to be helped, but there are challenges identifying people, as they tend to conceal their incontinence. The NCA WASH Advisor, has helped the team to develop a questionnaire in Kobo, which will be used to understand people's needs. The team were still considering what might be handy in this support and consulted a doctor / health specialist for advice. They considered the Ukraine dignity kit lists, as a basis to start from and added a few more items. At the time of the interview, they are considering to include: diapers, baby cream with zinc, bed pads, razors and scissors, but the kits are still being developed.
Successes	• Hygiene kits, including incontinence items, have been developed for people in collective centres and also for people on the move. • So far, distributions of incontinence items have been made in in Mykolaiv and Kramatosk areas. People received them, when they were referred for help for food or hygiene kits and when collecting them, the were asking for diapers for older people. The people who have been collecting them, have tended to come and say that 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 diapers, are adapted to each individual person 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 other parts of 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. • They are also planning more kit distributions, as well as hygiene promotion sessions, and the programme is also planning to provide some support to communal centres and IDPs and on water and sanitation. Additional budget has been identified for this next step.
Challenges	• The HEKS-EPR team did not previously have a staff member with WASH expertise, so a NCA WASH Advisor has joined the team to provide WASH advisory support. This includes helping establishing the WASH needs and assisting with designing appropriate solutions. • The difficulty of identifying people with incontinence.
Opportunities for the future	• The learning on what works for distributing incontinence-related NFIs, which involve different sizes, will also be useful for learning for other organisations. • Having a more generalist, non-WASH specialist team, supporting NFI distribution for people living with incontinence, has highlighted a need for guidance to be prepared with this group of professionals in mind. It will be important to not assume prior knowledge or experience in WASH when selecting and distributing such items. This important consideration, applies across all agencies.

CS-NCA-H – 2022 – DCA – Bangladesh – Opportunities for ASRH engagement

Focus	**Opportunities for engagement in incontinence through ASRH services**
Location	**Rohingya Humanitarian Response, Cox's Bazar, Bangladesh**
Dates	The second major influx of 1.3 million Rohingya people came from Myanmar in 2017
Context	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 in the whole response, had less attention, even though there was an HP sub-group. The local partners, have been: • NGO Forum – WASH components • Friendship Bangladesh – ASRH component The NCA MFA SPA funded programme in Bangladesh, is being phased out at the end of 2022.
Activities	• DCA supports two primary health care centres (PHC) and one women-friendly space. They work on family care, health care and ante-natal and post-natal care and provide all services other than deliveries. They refer mothers to health facilities for deliveries. • They also run awareness programmes, mostly related to SRH. These are on: family planning, ante-natal and post-natal, safe delivery, abortion services, post-abortion care and menstrual regulation. • The GBV team also runs women-friendly spaces in the camps. • The NCA programme, has not yet done anything pro-active 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 most women do not come for assistance on these particular issues, their problems only being identified when they come for other issues.
Successes	• The DCA SRH team have provided some support for fistula, such as referrals of women with fistula to the local fistula hospital, the Hope Foundation Hospital, near Cox's Bazar, which is also supported by UNFPA and UNICEF.
Challenges	• The subject of incontinence is a taboo subject, which poses barriers for engaging with people living with this issue.

	• The programme is not yet pro-actively working to identify and support people living with incontinence. • Staff do not have specific experience in this area, so capacity building would be needed to strengthen the programme in this area going forward. • A FGD held in 2018[2] with traditional birth attendants (TBAs) linked 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, and many young women and girls are married, between the ages of 13 to 20 years of age, with some women around 20 years of age, already having had between 2 to 4 children. Therefore, there are expected to be cases of fistula in such young mothers. This was confirmed by the Hope Foundation Hospital in Cox's Bazar to occur. It was assumed at the time, that this was because by admitting this problem happens, they may have then felt they were admitting, that they are not very good at their jobs. This formed a barrier for the TBAs, to be willing to acknowledge and discuss this issue.
Opportunities for the future	• The fact that the DCA/NCA teams have already established PHC, SRH/ASRH and GBV services, with professional staff such as doctors, nurses, midwives and other staff, offers opportunities for entry points, to be able to meet people living with this condition, and to share information and provide support. • The PHCs are also networked in with the Rohingya and host community TBAs, so they could also offer and opportunity to raise awareness on this issue. There is a need to refer more women and girls giving birth, to health facilities to reduce the risk of obstructed or protracted labour. • Advocacy with the local health sector, government bodies, and implementing NGOs/INGOs, to incorporate incontinence, into currently used IEC materials, awareness messages and modules, for refugees and host communities.

[2] House, S (2019) *Strengthening humanity in humanitarian action, Gender, GBV and Inclusion Audit of the work of the WASH sector in the Rohingya Response*, Cox's Bazar, Bangladesh, Main report (p72) https://www.humanitarianlibrary.org/resource/strengthening-humanity-humanitarian-action-work-wash-sector-rohingya-response-gender-gbv

CS-NCA-I – 2022 – Somalia – FGM and fistula

Focus	**Fistula and FGM and opportunities for GBV and WASH engagement**
Location	**IDP settlements in rural and town areas, Somalia**
Dates	The programme began in 2011, when people have been displaced by floods, drought, conflict and fast onset emergencies
Context	NCA programme in Somalia – The programme works in rural areas and in town centres with IDPs. 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 between pastoralists and farmers are not so common. Conflicts tend to be clan-based, between different pastoral clans. Conflicts are often related to water, for example, related to wells near a river and tanks and pumps. So, NCA tries to ensure water points are put in each different community, to reduce these risks. Gender context – 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. There is a move in Parliament, to discuss some of the sensitive issues and to rally women on these issues. 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 because of this, which also has health implications. FGM in Somalia and links with incontinence - Children face FGM from the age of 8 onwards. It is understood that 98% of women and girls undergo FGM in Somalia[3], and through this, all are considered as survivors of GBV. Women and girls who give birth, face their stitching being ruptured and then are stitched up again. As identified through latest analysis globally[4], women and girls with the more severe forms of FGM [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.

[3] https://www.legalactionworldwide.org/where-we-work/somalia/female-genital-mutilation-fgm/

[4] Pooja Sripad, Charity Ndwiga, Tamanna Keya. May 2017. *"Exploring the association between FGM/C and fistula: A review of the evidence".* Evidence to End FGM/C: Research to Help Women Thrive, New York: Population Council.
https://knowledgecommons.popcouncil.org/cgi/viewcontent.cgi?article=1593&context=departments_sbsr-rh

Activities	Current efforts on GBV and FGM by NCA and partners in Somalia – • UNFPA is working to promote zero-tolerance in different populations in Somalia and some people are reducing the practice of FGM. 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. These activities are funded through the Norwegian MFA. The NCA WASH programme – • The emergency WASH programme, focusses on water trucking, provision of hygiene kits, latrine construction by the IDPs themselves, establishing water kiosks, pipes in camps and provision of MHM sanitary kits for women • The development WASH programme, focusses on public, private partnerships and sector activities related to water sustainability, through construction of water systems. These are mostly boreholes and solar pumps along rivers and strengthening capacities in implementation. They also supported the development of the National Water Policy, 2016. MHM activities – • Traditionally for the management of MHM, holes were dug and women and girls sat around on the ground on the holes, so everybody knew that someone was menstruating. • The WASH Cluster, 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 cloths. In the HP activities, the team engages with the girl and these girls get kits. The programme provides new fabric and they can choose to use their old fabrics for menstruation and use the new one for clothes. • Items in the hygiene kit includes – 20 Litre jerry can (rolling ones to push using the leg), or a choice of a bucket, or basin instead; soap and drinking water chlorination tablets for 3 months; and cloth (for MHM).
Successes	The programme is already working on the prevention of FGM, which also has impacts on reducing fistula risks and is providing some funds for fistula repair. In addition, it also provides access to water and to NFIs for displaced populations. It encourages construction of toilets near the home, all of which will be useful for people with incontinence.
Challenges	• The programme is mostly working remotely, so it is harder to supervise new activities

	• When the programme goes to work with the community to work on hygiene promotion and to offer support, this opens up some opportunities to engage with women. • There is also a male staffing culture in Somalia, which makes it very difficult to talk with women. The team has a female staff member, who talks with women about menstrual hygiene, but more female staff are needed to have these conversations. • People with disabilities struggle to get access to water, and are often hidden in their house. Some have this hidden issue of incontinence, which poses significant challenges. • So many people must be living with this condition, but this is not specifically reflected in the WASH programme, so far. Some people will tell you about people who live with this condition. This can be one way to reach people, through the family, but then the person themselves, will ask how did you know this? So, it is a sensitive subject. • Blanket distributions would be easier and would reduce the sensitivity-related challenges, but this would also be expensive for the supply of pampers.
Opportunities for the future	• People need information and knowledge on the subject of incontinence and to understand its links to FGM. • 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. • It could also be useful to expand the NFI kit, to help people to more effectively manage their incontinence. • To undertake awareness creation on the needs of people with disabilities, by making some latrines accessible. This would also contribute to awareness creation. It would be saying, it's OK to have disability-related challenges, don't feel shy and we understand and will try to provide support.

Section 2

Global Humanitarian Actors Humanitarian response case studies

NORWEGIAN CHURCH AID

actalliance

CS-GHA-A – Syria/Jordan/Lebanon – Loving Humanity – Washable products

Focus	**Support for people with disabilities and supply of incontinence pads to refugees**
Location	**Production of washable pads by Loving Humanity to Syrian refugees in Za'atari Camp, Jordan, Lebanon, South Africa, Sierra Leone, and in Palestinian camps in Jordan**
Dates	Loving Humanity support for people living with incontinence - 2014 – 2022
Context	This case study, documents the development of washable incontinence products by Loving Humanity Charity and their supply for refugees and other people in LMICs. The charity, Loving Humanity, was founded by Amy Peake and provides menstrual hygiene products, nappies and incontinence pads, to some of the most disadvantaged people across the world, particularly people living in poverty and refugee situations. Amy became aware of the problem 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 at the time, and bedwetting was a major problem amongst the children coming over the border 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 (1-18 years of age), were bed-wetting, due to the trauma of what they had seen. In response, UNHCR had given everyone nappies / incontinence pads, which were of poor quality and not sourced locally. They were given to children under 2 years of age, as well as older people and people living with disabilities. After a while, it became apparent that this was costing the UNHCR a fortune, and they completely stopped supplying products to the refugees in the Za'atari camp. This meant that families found it almost impossible to keep everyone clean.
Activities	Amy was able to source 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. **Moving the factories out of Jordan and into new locations:** 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 many of the products. And they now export to a care home in a township in Cape Town, South Africa. And washable menstrual pads, to Burundi and Sierra Leone. As well as baby nappies to Palestinian camps in Jordan. Interestingly, highlighting the cultural differences between countries, it was noted that they do not supply washable menstrual products in Kenya, due to taboos in the country.
Successes	The Loving Humanity Charity, has supported the establishment of a number of factories, to make washable sanitary, incontinence products and babies' nappies for refugees. **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 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 a plan to set up a factory in Sierra Leone to produce washable pads  **Loving Humanity washable products**
Challenges	• There have been several political struggles within the humanitarian sector, that have made things more difficult, including large meetings, where the atmosphere was uncollaborative, and very frosty.

	• Humanitarian organizations don't always have the knowledge, to ask people about incontinence, or the staff are not senior enough, to make big changes possible. The exception, being an excellent UNHCR colleague, who was in a relative position of power, and the social workers at the camp, also identified the problems (of bed-wetting) quickly. • There is also the issue of shame, with many people too embarrassed to ask for help with incontinence. For example, on asking 5 women working in her factory, whether they had any direct experience of the issue, the problem of stress incontinence due to pregnancy and childbirth came up. With some women having had nine children. She then asked them to compile a list of friends and family, who might benefit from the products they were making, and Amy was shocked when they returned the list with 50 names on it. • General practical problems, such as difficulty sourcing materials. For example, early in the project raw materials (wood pulp), was sourced from India, to be used in their disposable products. But it often arrived in poor condition, because it wasn't packaged well, and water and pests had got into the material. Hence now before being transported, the material is properly sealed in plastic.
Opportunities for the future	• Loving humanity has 9 patterns for their nappies and incontinence underwear (3 designs for babies, 3 for children, and 3 for adults). They distribute the products (washable nappies/pads) which are free. And they are always trying to find new people who need our products. So, this opens up the opportunity for other humanitarian actors to source these products. • The main aim at Loving Humanity is very simple, they *'Just want to get nappies and pads on people'.* So that people living in difficult humanitarian situations, such as refugees and people in poverty, can have a dignified life. • To see two videos with: a) feedback from a beneficiary, of the Loving Humanity babies' nappies, and b) also a video of the menstrual hygiene / stress-incontinence washable pads and Loving Humanity colleagues who run the micro-factory in Jordan. Included is also a flyer of the Loving Humanity washable products: https://drive.google.com/drive/folders/1hXRYlim8qB0SUotkv1hKoZftTQTzy661?usp=share_link • Loving Humanity website: www.lovinghumanity.org.uk

CS-GHA-B - Ukraine – Global WASH Cluster taking the lead on incontinence in Ukraine

Focus	**Global WASH Cluster taking leadership on incontinence in Ukraine**
Location	**Ukraine – Eastern Ukraine (2014-2022) and the current (2022) responses**
Dates	2016 - 2022
Context	 **Mark Buttle, WASH Cluster Coordinator, Ukraine, Crimea Response, 2016-2021** Mark Buttle was the WASH Cluster Coordinator in Ukraine from 2016 to 2021, during the conflict in eastern Ukraine. He also provided 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 sector coordination groups to also take action on the incontinence issue. **Becoming aware of the demographic** - When Mark was in his induction phase, during his first assignment in 2016, HelpAge and HI were actively reviewing HI-supported guidelines on people with disabilities for humanitarian responses[5]. Soon after arriving, he attended a workshop, which talked about the guidelines and there were a lot of people talking about the demographic of the people affected by the humanitarian situation. Later there was a large meeting to develop the Humanitarian Response Plan (HRP) for Ukraine, when 40 or more agencies and around 200 people, met in one place. They developed the HRP in 2016 for 2017. However, there was also a lot of discussion on the older nature of the affected population, so he became aware of possible incontinence issues early on.

[5] In 2016, the United Nations Inter-Agency Standing Committee (IASC) Working Group agreed to the establishment of a Task Team on the Inclusion of Persons with Disabilities in Humanitarian Action, which drafted the Guidelines on Inclusion of Persons with Disabilities in Humanitarian Action. Through: https://reliefweb.int/training/3521764/persons-disabilities-humanitarian-response-new-guidelines-more-inclusive (can't access); Charter on Inclusion of Persons with Disabilities in Humanitarian Action: http://humanitariandisabilitycharter.org/

	Key drivers – older people remaining at the front line - Key drivers also included the situation on the front line. In contrast to younger people and families, many older people refused to move, or could not move, or did not have prospects to leave, to go somewhere, compared to where they are. They might have lost their pensions, and suitable accommodation certainly could not be guaranteed. They were concerned to move where they didn't have anything. Parents with young children moved quite quickly, leaving behind the older people in the villages. So there ended up being over 70 villages, considered as isolated settlements, along the line of contact, where many older people were left behind, not to mention hundreds of towns, a little further from the fighting. These front-line villages, became the worst villages in the response. This is apart from the so-called 'non-government-controlled areas', where there was also an older demographic.
Activities	**Start of work on incontinence** - Some agencies, such as ArcheNova and New Way, piloted the distribution of toilet chairs, which went down well with the recipients and the sector supported this. Meanwhile, it also became obvious that bed pads and adult diapers, would be needed. The response was almost a forgotten crisis for some years, and WASH organisations, together with the WASH Cluster, were working to identify response modalities, that were a bit different in approach to other places, which could also help to focus the world's attention on the Ukraine response. So, given the large numbers of older people in the affected population, WASH actors and the cluster, worked with HelpAge going back and forward, to find out what was needed: • WASH agencies, realized bed-bound people, and people suffering from incontinence, were suffering during their time in bed; and hence they identified bed pads as a solution. They also identified, that distributing diapers and bed pads, was a simple level of programming, and hence that the humanitarian community could relatively easily, engage with this issue. • Cluster agencies, recommended to include a range of incontinence diapers of different sizes, including for both adults and children. They found that it was easier when the diapers are supplied separately, from the widely distributed hygiene kits, as then the size can be selected at the time of pick up. For example, if the person collecting them, takes them from a supply in the back of a lorry, or when delivered to their door, this is simpler. **Costs** – Market analysis completed by Food Security teams, also noted that adult diapers in the conflict area, were more expensive, and, to make things worse, the logistics of supplying such diapers, to supermarkets near the frontline, were failing. In the areas of fighting, local shops probably also do not have some items at all. In the case of Ukraine, there was an approximate 25% premium added to the cost of hygiene items in shops, as they got nearer the front line. In 2018 WASH actors, used a 'common sense' approach and established a Hygiene Technical Working Group (TWiG), which considered, more systematically, what items to distribute.

Some agencies preferred to distribute vouchers, and it was that process, that started to highlight the real cost of supporting families, with people with incontinence. If even supplying two pads a day, for an individual, which is nowhere near enough, buying adult diapers would still add around USD 60 to the family budget, every month. Normally the cost of hygiene items distributed, was estimated to be around USD 10 / person / month. So, buying adult diapers was a massive addition to the family budget. The purchase of babies' nappies, if required, caused a similar financial burden: an additional USD 35 approx. / month.

Vouchers - Efforts were made in supporting shops, through Triangle Generation Humanitaire's (TGH's), electronic voucher system, implemented in partnership with UNICEF. Families received an SMS alert for an appropriate voucher, which they could then spend in a local store. The store had a laptop or smartphone, and could redeem them against the voucher number. The e-vouchers, could also include options to purchase incontinence items, and were tailored to each families' needs.

Stigma – In Ukraine, there did not seem to be significant problems with stigma preventing people asking for help. However, distributed kits containing adult diapers, were in any case, named **PSN kits (People with Special Needs),** in order to reduce any embarrassment. People who needed the products, were quite direct and asked for them, as well as asking for additional washing powder, soap and shampoo. They just needed to know, when and where they could get hold of the items.

Hygiene kits – In Ukraine, the WASH cluster Hygiene Technical Working Group, made sure that the design of hygiene kits, considered incontinence issues. In addition to **"normal" Family hygiene kits, a smaller "Small family hygiene kit",** was designed, aimed at the needs of a more elderly couple, or an older person, or disabled person, plus a carer, living together, which could be distributed in parallel with a new kit, for People with Special Needs (PSN kits). They used this name, to try and get away from the stigmatized term 'incontinence'. Kit items can be seen in the two tables, which follow at the end of this case study.

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WASH Cluster coordination actions – influencing current (2022) response

Sadly, in Ukraine, not all the incontinence-related programming, has been continued, in 2022, given the huge number of new WASH actors in the country, and given the challenges of scaling-up a humanitarian response, during an active, and country-wide conflict.

Initial briefing with WASH Cluster actors - Another WASH sector actor, explained how Mark Buttle, as the WASH Cluster Coordinator, did an initial briefing for all WASH sector representatives, from organisations planning to work in Ukraine. During this briefing, he talked clearly about the need for WASH sector actors to support older people with any incontinence issues. This set the

	scene, for what was expected of WASH sector actors, during the scaled-up response, in 2022. **Hygiene promotion guidelines (2018) –** These were already developed for the eastern Ukraine response and included recommendations around incontinence needs. The WASH Cluster guidelines, 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, may have additional needs: *'The WASH Cluster Hygiene Technical Working group estimated the cost of hygiene items for voucher calculations at 300 UAH per person per month in GCA areas. However, an additional 1750 UAH per severely disabled adult or 1000 UAH per baby under 3 years is also appropriate. Therefore, when planning voucher distributions WASH Cluster partners are encouraged to identify specifically those groups (with older, disabled or babies in the family); to gather data carefully regarding the numbers of target beneficiaries as the presence of babies and disabled or older adults has a massive effect on the need for support'.*[6] The hygiene guidelines from 2018, were shared with incoming WASH Cluster Coordinators, in 2022. However, it remains to be seen to what extent it has been possible to maintain the incontinence programming measures, within the huge response in Ukraine, in 2022. **Hygiene kit lists** – Hygiene kits for the 2022 response, were adapted from the kit lists developed during the eastern Ukraine response.
Successes	From 2017 or 2018, until 2021, there was widespread support for older people and people with disabilities, through additional small family hygiene kits, as well through the distribution of incontinence-focused "PSN kits", or via the distribution of vouchers to cover their purchase. Toilet chairs were also distributed by some agencies. It was a significant achievement, since action on supporting people with their incontinence, on this scale across agencies, has not been recorded in the same way, in any other humanitarian response globally. The actions of the WASH Cluster in Ukraine, have also offered an opportunity to raise awareness on the incontinence issue, with a range of actors, some of whom may have not worked on this issue before. It also offered opportunities to learn through practice, in trying to provide this support.
Challenges	**A range of useful lessons came from the experience in Ukraine:** • **Creams** – WASH Cluster agencies tried to add Zinc oxide ointment, as a barrier cream, however it was difficult to distribute the item, as it is classified as a pharmaceutical product. Many agencies were not able to distribute barrier cream, without medical supervision. Key donors, such as the USAID Bureau of Humanitarian Affairs (BHA), were also unable to finance such distributions, for legal reasons. An alternative to barrier

[6] Exchange rates: From 2016 and 2021, one USD was around 25-30 Ukrainian Hryvnya (25-30 UAH)

	creams, of distributing baby powder and baby moisturizing cream, was suggested. • **Underwear** – There may also be a need to consider underwear, as is considered for MHM kits. There is a need to check whether someone has underwear or not, when considering incontinence-related distributions of incontinence pads or adult diapers. This issue was not explored in Ukraine. • **Laundry in hospitals** – Some work was successfully implemented to improve laundry in hospitals, by Premier Urgence International (PUI), and others. It was identified, that there is often a need for waterproof mattresses in hospitals, as well as improvements to hospital laundries. • **Solid waste** – In humanitarian situations, there is still a gap related to dealing with solid waste management of soiled adult diapers, which can become big volumes quite quickly. It is a nasty waste, and soon becomes a big pile. In Ukraine solid waste management is a challenge in some areas, even in normal situations, so this added challenges on top. • **Infectious wastes in hospitals** – Sadly infectious waste in hospitals, in Ukraine, also tends to be not separated properly, often bagged in the wrong color bags, and collected by a private contractor. It is also often very unclear where such waste was disposed of, finally, as there seemed to be a shortage of incinerators. It is possible, that contractors did not always dispose of infectious waste properly; and it was extremely difficult to check. Also difficult, was the installation of any new medical waste incinerators, since the regulations on air quality were prohibitive.
Opportunities for the future	• Widespread action supporting older people with their incontinence in Ukraine, was clearly been enhanced by the WASH Cluster Coordinator'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. • The coordinator at the time, Mark Buttle, saw his work as simply focused on coordinating multiple agencies, to consider appropriate aid to the (at the time) to the elderly 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 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 they were expected to act.

	• The Ukraine response is unique, in leadership coming from the WASH Cluster coordination team, on the issue of incontinence, and is an excellent example of good practice. • It is hoped that other WASH Cluster and other cluster coordination teams, will learn from the Ukraine example. It would be very positive, to see this case study, discussed in any global training for new WASH Cluster Coordinators.

Small Family Kit Contents - Eastern Ukraine (last updated March 2018)							
№	Price per Kit (UAH, GCA)		Price per Kit (RUB, NGCA)		Description of items	WASH Cluster Recommended Kit	
	Lower Price	Upper Price	Lower Price	Upper Price		Per Month	Comment
High priority Items (all organisations and agencies should include these if possible)							
1	20	100	30	150	Toothbrush	1	2 pieces minimum distribution
2	20	50	100	150	Toothpaste	100 ml	
3	40	100	70	110	Soap bars	2 x 75 g soap (300 g total)	
4	50	120	150	200	Shampoo	250 ml	
5	80	180	200	275	Washing powder for clothes, universal and hypoallergenic	1.5 kg	
6	7	15	20	50	Bleaching, disinfection powder	1 container of 200 g size	
7	30	50	75	120	Dishwashing gel / Washing-up liquid	500 ml	
8	40	200	200	380	Packs of hygiene pads	2 packs (1 pack of 4 dots, 20 pcs in a pack and 1 pack	

						of 6 dots (night), 14 pcs in a pack)	
9	13	25	65	100	Toilet Paper	2 rolls	
Second priority Items (these items are optional)							
10	7	15	20	40	Laundry soap	100g	Minimum distribution 1 bar of 200-250g
11	15	25	20	35	Sponge for washing dishes	1 pack of 5 pcs	nice to have
12	10	20	25	45	Garbage bags	1 pack of 30 pcs	Some areas burn garbage at household level
13	40	80	150	250	Disposable razor	1 pack of 5 pcs	requested by men
14	100	200	400	600	Towels	2 pcs (standard size)	One off distribution only
15	40	60	200	250	Plastic bucket	1	One off distribution only
16	10	40	20	30	Wet Towel Wipes	2 small packs (15 wipes per pack)	nice to have
	522	1,280	1,745	2,785	Additional Comments	Kit is aimed at a small family with only 2 people	

People with Special Needs Kit Contents - Eastern Ukraine (last updated March 2018)							
№	Price per Kit (UAH, GCA)		Price per Kit (RUB, NGCA)		Description of items	WASH Cluster Recommended Kit	
	Lower Price	Upper Price	Lower Price	Upper Price		Per Month	Comment
High priority Items (all organisations and agencies should include these if possible)							
1	60	90	270	450	Wet Towel Wipes	3 packs of 120 pieces	
2	80	200	70	120	Gloves	2 packs of 5 pairs	
3	800	1,000	1,600	2,200	Diapers for adults	2 packs of 30	A large variety of size options should be considered by agencies, including Extra Small (XS) Adult size, which could be used for children with special needs.
4	250	350	550	750	Absorbent pads	1 pack (600 x 600 mm)	Agencies may wish to consider larger size absorbent pads.
5	80	200	380	380	Zinc ointment (10%)	2 tubes of 20 g	Alternative items are useful to consider as sometimes donors object to zinc ointment: Baby powder plus baby moisture cream
Second priority Items (these items are optional)							
6	40	100	70	110	Soap bars	150 g total (for example 2 x 75 g	

						handwashing soap bars)	
7	80	180	200	275	Washing powder for clothes: Universal and hypoallergenic	1.5 kg	
	1390	2120	3140	4285	Additional Comments	Note 1: This kit is for one person living with a disability or with other special needs, for one month. Agencies should multiply the quantities to design kits suited to their own programming. Note 2: It is recommended by the WASH cluster to include all High Priority Items. Agencies can nevertheless adapt this kit to suit their own programming, especially considering whether to use Second Priority Items. Note 3: It is assumed that PSN kits will be used alongside a Family Kit or a Small Family Kit, so people living there should already have some basic hygiene items.	
Removed items (these are either not necessary, or more suitable only for first phase, when IDPs are on the move)							
					Toothbrush		These items are included in other kits
					Toothpaste		These items are included in other kits
					Shampoo		These items are included in other kits
					Toilet Paper		These items are included in other kits
					Baby moisture cream		Use only as an alternative (see above)

CS-GHA-C - Ukraine – Incontinence actions across contexts in Ukraine

Focus	**Humanitarian agency actions across contexts on incontinence in Ukraine**
Location	**Ukraine**
Dates	2022 Also see the following case studies: • **CS-GHA-B- Global WASH Cluster taking the lead on incontinence in Ukraine** • **CS-NCA-G – HEKS-EPER – Ukraine – Non-WASH actors working on incontinence** • Also see **Section 5.1.6** – for the use of the shopping trolleys in Ukraine, by NRC, for older people to carry their NFIs
Context	This case study shares experiences of a number of organisations, who have been working 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 working on this issue on a larger-scale and undertaking great work on this issue. This includes: • A - Age and Disability Working Group – supported by HelpAge • B - Norwegian Refugee Council – working across contexts • C - Polish government – quickly installed support to people with disabilities • D - Humanity and Inclusion – learning how to learn what is needed • E - RedR – training for the WASH Cluster (2020) • F – OXFAM – provision of NFIs with donation support
Activities	**A – Age and Disability Working Group – supported by HelpAge** There is an Age and Disability Working Group in Ukraine – HelpAge are supporting this and they have provided advice and worked closely with the WASH Cluster.

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B - NRC – Supporting people with incontinence in different contexts

There were clearly a large number of older people among the people in need, a higher proportion of older people than other emergencies. Conscription also took some of the younger people away, so the balance was more unequal than in other emergencies. In addition, the context, required an adaptation to the items in typical hygiene kits, due to people being used to different products.

The hygiene kit composition already existed when the war started in mid-March 2022, which included some incontinence items. It was initially a bit difficult to grasp the background and the emergency guidelines, but as the cluster standards included the older kit, a conversation was not expected, as the content was already identified. In the older kits, this included powder for the body, disposable wet towel wipes, pads for the bed and diapers (sizes S, M, L). they also provided top-ups.

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. See the table which follows.

Table 1 - Learning by NRC from working in different contexts in Ukraine

People trapped in the Donbass region in the East	In the East, people were trapped in the Donbass. They were living most of the time in bomb shelters. Eastern volunteers were involved in getting items to the people in the bomb shelters. Within the shelters, people showed each other solidarity. Quite a high ratio of kits was given - 1 family received 2 older and 1 baby kit per family. NRC supplied a mix of sizes of diapers in the kits, and people exchanged them as required.
Older persons/ care homes in the North	Large numbers of older people were hosted in older persons/care homes. They are struggling and feeling desperate managing the incontinence issue, particularly because of soiling of mattresses. So, they needed to prevent them being soiled. But on the positive side, people working on this issue in government and state-run facilities, knew the products they need and the standards. They were just missing the budgets. In in April, in the North, care homes also requested hygiene kits and older kits for care facilities. There were both very old people and people with mental health conditions, living in these care homes. NRC provided a ratio for 3 months, of 1 kit per older person and other residents of the homes. Each kit had 30 pieces within the pack for each month. Also supported female beneficiaries with menstruation materials. People could exchange the sizes between each other as needed.

	On reflection – this number is lower than the needs, as it works out at 1 pad per day, and a person can use multiple pads, in a day and night. This number was based on assumptions and not on a detailed study, or statistics, as the team are new to work on this subject. But even with these low numbers, these contributions would still have been very valuable for the care home to manage incontinence of their residents. Firstly, not all residents may live with incontinence. Some may only have occasional, or lighter problems with it, and the care home may have some stocks, that they can also add to the donated items. So, the items could be prioritized to the people who needed them most. These distributions were still very positive. This is also a learning process for most actors, and it isn't until we start on this work, that we can learn for future interventions.
Hard to reach areas	First distributions were undertaken in hard-to-reach areas. They had private funding for these items. They managed to do a few surveys on the phone, but they have not been able to do more comprehensive PDMs. So no feedback has been obtained on distributed items and they were unsure about the actual quality.
Collective centres in West of Ukraine	NRC also provided some support to institutions, providing collective centres in West of Ukraine. For these distributions, they had institutional donors. They agreed the population profile and tailored the kits as standard for distribution.

B - Humanity and Inclusion – Learning to establish needs

- **In Ukraine HI started by working in institutions** – They asked themselves what support should we provide? The policy is often seen as distributing 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.

C – Government of Poland 'Blue Dot' support for refugees with disabilities

- **Support for the refugee response** - There is an excellent example from Poland, where the Government set up a system of support for the refugee response, which was set up quickly. It allocated USD 17 million, funding for this response. The Secretary of State for Disability was responsible for the funding and programme. This included two key aspects:

  The first support included:

  - Provision of access to assistive devises 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. The process was reported to be was well designed
  - 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 support included -

  - Set up in a very short period - the government then gave access to refugees, to social protection benefits and disability benefits, on level with Polish citizens
  - They had 1,700 applications and 400 were already processed

It was a very positive effort -

- It was led by the Secretary of State, who also has a disability, who has been a strong advocate to make sure this gets prioritized
- The Secretary of State has also been pushing UNHCR and other agencies to be more efficient
- It is a high-income country environment, but also has shown positive practices that can be learnt from for other contexts

But the main problem with this system was -

- 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
- Around 10% of refugees accessed this 'Blue Dot' support – of these people, most were women and children who accessed the support (people with disabilities, older people and people with chronic conditions)

Health sector processes -

- There have also been some more traditional cash transfers, through Health sector processes

See the weblink for more information –

Pomoc dla obywateli Ukrainy z niepełnosprawnością na zaopatrzenie w wyroby medyczne – Państwowy Fundusz Rehabilitacji Osób Niepełnosprawnych (pfron.org.pl)

English translation – start of the information provided on this link:

Supply of medical devices - support for refugees from Ukraine

PFRON offers assistance in financing the required deductible in the purchase or repair of medical devices issued on request. A citizen of Ukraine with a disability may receive this assistance under Module I of the PFRON program called ***"Assistance to Ukrainian citizens with disabilities".***

Who Can Benefit From Help

You can benefit from assistance if you are a citizen of Ukraine with a disability and meet all of the following conditions:

- *Your stay in the territory of the Republic of Poland is considered legal, pursuant to art.*
- *2 clause 1 of the law on assistance to Ukrainian citizens in connection with an armed conflict in the territory of that state.*
- *You have a document confirming the 1st or 2nd degree of disability issued under the Ukrainian system of certifying disability, and in the absence of it, a declaration that you have one is enough.*
- *This also applies to children, in this case the guardian's declaration that they have such a document issued to children under the Ukrainian system of certifying disability is enough.*

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D – RedR support for training in Ukraine

- RedR provided some training for the WASH Cluster on the 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.

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E – OXFAM – Support for NFIs, including donations

- In Ukraine OXFAM also included incontinence products in the hygiene kits, without advocates trying to get this on the agenda 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 of adult and child incontinence, where volunteers would find the beds wet in the morning.
Successes	• A training run in Ukraine in 2020, by OXFAM on WASH project cycle management, incorporated a module on inclusion, which also included incontinence within it • There have been significant successes in terms of providing support for older people and people with disabilities with their incontinence needs • The Polish Government provided very quick support for refugees with disabilities, who could show they had a disabled persons card, once people arrived in Ukraine • Plus, also starting to learn on how to practically support people with their incontinence in a large-scale humanitarian response, working across diverse contexts • This has been the only response globally, with all WASH actors expected to provide support for older people on incontinence
Challenges	One of the challenges shared by HI, was over their thought processes, as to how to do the distributions of items related to incontinence: • **Questions were asked** - on how to establish the distribution processes and decisions: o *'What triggers us to provide these top up kits?'* o *'Do we systematically provide the kits for older people and people with disabilities?'* • **The team didn't want to make assumptions** - so they decided to: o Wait to see if people mentioned the issue and then gave them the kit o Insisting on 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 o The WASH team were also planning to do some quick KIIs and PDMs to help get a basic level of understanding in the first wave of an emergency. It was hoped to do these quick KIIs, to try and demonstrate it isn't so difficult to get this information on needs, but this work has not yet been completed, due to a change-over in staffing. o This approach isn't felt to be perfect, but was felt to be better than only having a single solution. HI intend to keep working on this and learning.
Opportunities for the future	• The learning that has happened in the Ukraine response, by NRC, has been very positive, particularly because they provided support for incontinence across a range of different types of contexts. Each has required a tailored response, which should be an example of good practice for future responses.

	• The learning by HI, also was very valuable, through working to establish new mechanisms to learn what people's needs are, rather than making assumptions • At this stage of learning on how to work on incontinence, all humanitarian actors are learning on this together, so all of these questions and experiences will add together, to help the humanitarian community to know what works better for future responses

CS-GHA-D - Vanuatu – World Vision – Supporting people with disabilities

Focus	**Support to people with disabilities in Vanuatu to manage WASH and incontinence needs**
Location	**Vanuatu in the Pacific**
Dates	2021-2022
Context	Vanuatu is an archipelago of 83 Islands in the South Pacific and is rated as one of the most vulnerable countries to climate-related disasters in the world. In 2019, World Vision Vanuatu and key partners, including the London School of Hygiene and Tropical Medicine, undertook an important large-scale study, to better understand the experiences of water, sanitation and hygiene for women and people with disabilities in the northern provinces of Vanuatu. Other partners included: Vanuatu Society for People with Disabilities, Vanuatu Disabled Person's Association and the Ministry of Justice and Community Services. The study asked similar questions to people with, and without disabilities, so there is a range of useful data and qualitative findings. **MHM and incontinence findings from the Vanuatu study on YouTube:** https://www.youtube.com/watch?v=030UQInPyWk **An infographic:** https://www.lshtm.ac.uk/sites/default/files/2022-01/WWD%20-%20Incontinence.pdf. One of the key findings from the study was that 1 in 3 people with disabilities surveyed, experience incontinence, three times per week or more. In order to manage incontinence, caregivers of people with disabilities reported restricting the intake of food and water for the person with disability, as well as limiting their participation in community activities. The project aims have been developed, as a result of some of the findings from this study and it is called *"Laetem Dak Kona".* This means to *"shine a light into the dark corners where people with disabilities are often hidden away"* and it aims to raise awareness of the challenges faced by people with disabilities. It also aims to provide ways to improve the overall quality of life, in sanitation and hygiene, for people with disabilities in Vanuatu.
Activities	Training and guidance materials: • **Training for carers** – It was understood that one of the ways forward, is to support carers to better understand incontinence and to provide some additional ways and strategies to management at home. The challenge was to not only raise awareness of additional strategies, but to also locate products and devices that caregivers can use, to better care for people with disabilities with incontinence at home. The most commonly available

product that is available in Vanuatu, are adult disposable nappies, so these are widely used, because availability of any other incontinence support product or training is very limited.

- Allison developed a training package for people with disabilities and their carers, to raise awareness of other strategies and products to help manage incontinence at home. The training package is called "LEFTEMAP LAEF" or *"Lift 'em up life"* – which means improving the overall quality of life of people with disabilities and their carers. These are not in-depth modules for every challenge faced by people with disabilities, but talk about different disability types and touch on personal care and hygiene, including incontinence strategies and products that are locally available in Vanuatu.

One of a series of posters developed by World Vision to raise awareness and build capacity on supporting people with incontinence in Vanuatu

- **Guidance documents** – For these, they were aiming for simple one-pagers to help raise awareness of different products that are locally available to support with incontinence. Carers training promoted 3 main options: a) Reusable mattress protectors and wash mitts that can be used to provide personal care in bed, for a person with mobility difficulties who cannot access a toilet; b) Reusable incontinence wear – Pads for both men and women that can be worn inside underwear to prevent leaks; and c) Portable toilet chair – for people who can transfer from the bed onto the chair, with a small amount of mobility, but are unable to walk long distances to access the household toilet, which is mainly located outside of the house. See the images of leaflets merged together into a banner, that is used at local events, to raise awareness of the products available locally.

<u>Reusable incontinence pads, mitts and mattress protectors:</u>

- **Worked on developing wash mitts and mattress protectors –** The WASH mitts are made from locally available face cloths, that are folded and sewn together along one side, to allow them to be worn on your hand. The fabric is soft and absorbent, so that you can easily wash off urine or faeces when changing an incontinence product, without touching it with your hands. Gloves are not easily available, due to access and cost, as well as contributing to environmental waste, so this washable mitt provides an inexpensive option, to improve hygiene for both people with incontinence and their carers.
- The Mattress Protector, is made from recycled rice bags, with an absorbent layer on top – with rice bag on the bottom. It can be used on a bed to protect the mattress from being soiled and wet, or the floor. The original prototype had wings on the side, so it could be tucked under the mattress, however this was found to be unnecessary in the local context, as many people did not sleep on western style mattresses. So the final product is a single rectangle shape with waterproof rice bag layer at the bottom and absorbent towelling layer on top.

Mattress Protector

Wash Mitts

- **Incontinence Pads for women and men** – These are made by a local company called **Mamma's Laef** (pronounced - Mamma's Life). Mammas Laef is a home-based social enterprise, that employs local women to sew reusable products. The business has grown as a result of the government banning single use nappies for children, and Mamma's Laef, have subsequently developed a reusable nappy for children and more recently

have started making these in adult sizes on request (as an alternative to adult nappies that were not included in the government ban). The reusable nappies, have a waterproof outer cover and an absorbent insert, that is changed each time is becomes wet. The waterproof fabric is from New Zealand, they can be washed in a washing machine.

  - Mama's Laef - https://www.mammaslaef.com/what-we-do/
  - Includes male pads, female pads and underwear for incontinence - https://www.mammaslaef.com/products/
  - Reusable babies' nappies - https://www.mammaslaef.com/baby-nappy/
  - Report of trial – https://www.mammaslaef.com/wp-content/uploads/sites/105/2021/02/FINAL-PilotStudy-FullReport.pdf

- Mamma's Laef also make menstrual pads and incontinence pads, in a variety of sizes. Women's and Men's incontinence pads, come in two sizes each. 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 located and they are slow with their mobility, so may not make it to the toilet on time. See photos below:

Women's Incontinence Pads

Men's Incontinence Pads

<u>Development of portable toilet chairs:</u>

- **Developed a portable toilet chair** – This is a commode chair, so that people can better manage their incontinence at night time – including in areas that are prone to natural disasters and bad weather / cyclones. Toilets are usually outside of the house and quite far way into the bush – the distance and the uneven terrain, lack of lighting and nothing to hold on to, all pose challenges for people with disabilities and who are living with incontinence. Some toilets were just two planks of wood over a hole. Hence bringing the toilet to the person, reduces dependence on others, to help the person go to the toilet. It improves independence and hygiene. For some people they also have to drag themselves on the ground, which puts them in direct contact with urine and faeces.
- **Process for development of the portable toilet chairs** - 'Commodes' was not a common term, so it was changed to 'portable toilet chair', which had

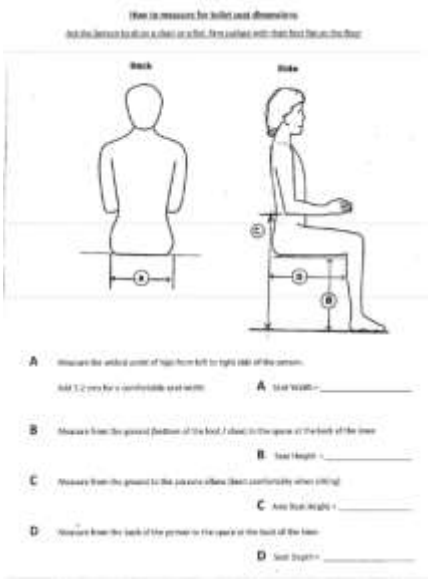
more acceptance. As it was not possible to get orders from overseas during Covid-19, as the borders were closed, and the chairs available in country already, which have been given through overseas aid, had become rusted because of the island state situation and hence disregarded in garden, it was concluded, these were not rugged enough. So, they made locally-made and sustainable products, using recycled pallets – using wooden timber and three coats of marine varnish and sanded. The recycled pallets were sourced at 5 AUD, but it may be possible to also use other wood. The chairs were made by a local carpenter and purchased for 100 AUD.

<u>Examples of adapting the chairs to different people's needs:</u>

- They made them suit the needs of each user. Some were made low, so they were easy to get on to for people who couldn't walk or sit in a standard height chair. One young girl, Shirley, was unable to walk and had severe contractures in her legs, meaning she could not sit independently on a standard height chair. Her toilet chair was made to be around 30cms high with anti-tip legs, so she could independently pull herself onto the chair, instead of having to pull herself along the ground to the toilet outside the house.
- For one woman who has lost both her legs, the chair was made extra wide so she could slide directly from her bed and then turn around easily using the wide arm rests.
- For one young girl with down's syndrome, the chair was made with no arm rests, as these were not required and it meant that the chair could be smaller to fit inside her house, which saved her having to walk long distances at night, which was very unsafe.
- One man, Kalmark, was unable to walk at all and he would crawl behind the house to go to the toilet and wife came behind him to cover it over. But then his wife passed away, so a chair was made, that he could put next to his bed (which was a mat on the ground) and was only a very small height from the ground, so that he could pull himself onto it using his arms.
- One woman, Janet, has severe Rheumatoid arthritis in her ankles and feet and so finds mobility painful and difficult and cannot walk even the short distance to the toilet. She was using a bucket underneath her bed, that she could access through the slats, when she needed to go to the toilet. Now she has a toilet chair next to her bed, that she can use.

<u>Resources:</u>

- Have prepared a report on the development of the chairs and case studies, with wonderful pictures of the owners of the chairs showing their delight – **"World Vision, Portable Toilet Chair Trial".** See links below.
- There is also a poster with practical information about the dimensions of the chair, and instructions on how to measure a person to build the correct size chair – see below.

	  • A series of great posters on the practical work, World Vision, have been undertaking supporting people with disabilities living with incontinence in Vanuatu – see link: https://drive.google.com/drive/folders/1zJXia_gAe3xkW9TbMDl_b8vJ6s8avE-9?usp=share_link • A short video 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 with toileting. Click on the link to see her video: https://youtu.be/oYFAWw0UCiw • A video on the support for VIP latrines for people with disabilities in Vanuatu - 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
Successes	• This project has come up with a number of practical, locally made solutions, which have already been appreciated by the users of the trial. <u>Examples of people supported with the toilet chair pilot</u>: • Some people have paid carers and that children may also have the burden of care for their parents, and they often feel overwhelmed, when they are thanked. One woman had to have her young son hold her over a bucket, which involved a lot of guilt and shame for the woman concerned, so the toilet chair was life-changing, for both of them. • Rebecca is an 80-year-old woman, with 6 children and has lost her sight. Her young grandson leads her into the bush to squat to go to the toilet on

	two sticks and she has to hold on to her grandson to balance. They found a very simple solution, by adding a handrail and a seat riser and for a personal chair in the house, so she can go in private. • Evana has had an amputation and her toilet was down the side of a hill. So, this project has helped with providing a toilet chair. <u>General benefit of the chair support:</u> • This helps all of the family and they can all be involved in the design. It can also assist them with reducing the amount of manual handling that needs to be done. It can make it safer, as it protects the carers back as well, as at the moment, they are lifting their relative, or other person they care for, and this can cause injury to both the person and the carer.
Challenges	• Challenges have included, keeping up with demand for the chairs • The fabric for the washable incontinence items, is not available in Vanuatu, so needs to be imported. This means the cost of the incontinence underwear, was much higher than the cost of importing from overseas.
Opportunities for the future	• It is really important to go and talk to the person and find out their needs, by doing this on this project, the solutions have been developed to suit their needs. • Reusable products can be made locally – bed pads, underwear, cleaning mitts. • Want to get to the point that people can buy these on the local market, so there is a need to train more people to make them. They could be made locally everywhere that people live. Vanuatu has 83 islands, and at the moment they are only available in one island. • These items can also be made by people with disabilities, who could start a business themselves. • Locally made toilet chairs, adapted for the person's needs, can be made easily using local materials, such as pallets wood or bamboo, which may be cheaper. • Carers need support and simple training, to help them know the management options for a person with incontinence. There are more options than just diapers and reducing drink and food intake.

CS-GHA-E - Global – HI – Supporting people with spinal cord injuries

Focus	**Supporting people with spinal cord injuries and other forms of incontinence**
Location	**South East Asia, Syria / Turkey border, Haiti, Ukraine, Afghanistan, Burundi**
Dates	On-going
Context	This case study provides an overview of the learning processes that HI and its staff and partners have gone through, while practically supporting people with incontinence over several decades. The experiences, come from working a diverse range of contexts, from South East Asia, the Syria / Turkey border, Haiti, Ukraine, Afghanistan and Burundi. Activities included, working in South East Asia with people with spinal cord injury, to help ensure an improved quality of life, and then across humanitarian contexts, such as Syria and Haiti. It was recognized that a range of different people can have continence issues, not just because of a specific condition, but also related to age and changes in context. They started to learn how to manage incontinence in older people during displacement, where people are cut off from their usual solutions for management. So, they looked for other solutions, including both disposable and reusable solutions. After the Haiti earthquake, HI also started to look more into incontinence. The physical rehabilitation colleagues, started discussing it more, a few tools were developed and there have been more discussions. 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 now working to structure their responses to incontinence more, as they continue to learn going forward. Some of the learning that HI has had in incontinence, is included in the following sections.
Activities	<u>People with spinal cord injuries</u> • **Incontinence management is a survival issue** – HI has been working on understanding how incontinence affects a person's quality of life, particularly related to urinary incontinence. They have recognized, that challenges in managing incontinence, still exist at community level when people go home to their families from hospital. For people with the condition of spinal cord injury, the issue of incontinence is a huge survival issue. • **Catheterization** – They found that some national authorities are balancing benefits and risks re catheterization. For example, they may promote self-

	catheterization with reuse of catheters, knowing the hygiene and UTI risks, as this solution is more practical and sustainable than using single use, as promoted by industry. This might mean having 6 Urinary Tract Infections (UTIs) per year, vs 2 UTIs. But they have decided this balance of risk, has more benefits and they will manage these. The local authorities should have the say, on if this risk is acceptable. • **Protocols for the management of spinal cord injury** – HI developed specific protocols to support people with spinal cord injury, together with the International Continence Society (who provided the basic framework based on international standards) and the governments in Vietnam, Cambodia, Laos and Thailand. In Vietnam, the MoH took over ownership of the toolkits, developed for people with SCI. HI has continued to develop this across countries and has developed material kits, mainly for catheterization, and has 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 or special toilet chairs. <u>Country learning experiences:</u> • **Syria – trialing reusable products** – In Syria, HI took the processes learnt in South East Asia, to establish linkages with existing specialist organisations, and condensed the process of establishing linkages, from 2 year to 6 months. In Syria, they took information from the International Spinal Cord (ISC) Society and the International Society of Spinal Cord Injury (ISCOS) platforms and tools. There is a large footprint from the needs. For reusable products, the challenges were linked to the availability on the local market, particularly related to catheters etc. In Turkey, disposable catheter products were available, but questions existed on where to dispose of them? For reusable ones, they can be imported and people provided with education and safe use. Then the users become much more involved in using and protecting their products. For reusable pads, more operational research is needed, as there are a number or risks, as they can be difficult to keep clean and dry in some contexts, where WASH is limited. So, they were not felt to be appropriate at the time, in the Syria response, because of this. • **Haiti – communication with people who have incontinence** – In Haiti, they targeted people living with incontinence, as HI saw it was a huge gap for households with people with disabilities and older persons with disabilities. They also realized, that when they distributed standard kits, these were not appropriate for everyone, so they needed to be more specific in what they provided. The question was how can they do this? They did this, through opening communication lines with people with incontinence issues and discussing what they needed. • **Ukraine – working with institutions and establishing needs** – They started by working in institutions and asked themselves what support should we provide? The policy is often seen as distributing 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, they have undertaken hygiene kit distribution, including baby kits and incontinence kits for top-ups. The question has been 'what triggers us to provide these top up kits?' Do we systematically provide the kits for older people and people with disabilities? But also, we don't want to make assumptions. So, HI decided to wait to see if people mention the issue and then give them the kit. They insisted on doing 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. They have also been trying to understand how to get a basic level of understanding in the first wave of an emergency, on the needs of people. The Global WASH Specialist was working on a process to do quick KIIs, to try and demonstrate it isn't so difficult to get this information on needs. It is understood that this approach isn't perfect, but HI felt it is better than just having a single solution.

- **Afghanistan – providing care at community level** – Here they identified people who are para and tetraplegic and have a simple list of products, which are provided in different stages, depending on the level of need. This is such as toilet chairs, male and female urinals, and provision of mattresses which can be cleaned and washed.
- **HI mobile teams in humanitarian contexts** – The mobile teams cover an area and establish needs, including for rehabilitation. They undertake outreach and provide services. During their visits they can ask about sanitation needs, but they do not have WASH specialists in the teams. This depends on the profile of the programme. They let people say what they need, in the same way that families of young children say they need diapers. The mobile teams focus on people with specific disabilities, such as people who are paraplegic and 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. Stigma and mental health are significant issues related to the management of incontinence.

<u>People with fistula:</u>

- **HI has also worked with people who have fistula** – This includes where their incontinence is not discussed. Women can be kept in a specific part of the house, as they are smelling, so efforts are needed to integrate them back into their family. If the family is hiding someone in the home, they may also be almost dying and facing trauma, so there needs to be follow-ups. They are often sent home with only basic support with no follow-up and this becomes even more of a challenge when people are displaced.

	• **People with disabilities, can also face sexual violence** – including in migratory environments. People who have faced such experiences, need to be identified in a very confidential way to provide support. • **Working with caregivers** – Incontinence needs to be directly addressed, including on the side of training of caregivers, whereas if the person is looked after in a hospital, incontinence needs can be easier to address in the hospital environment. • **Fistula surgery and physiotherapy** – In Burundi HI worked together with MSF (2012-15) and ran a fistula surgery programme for 7-8 months. Continence still needs to be restored after surgery, so physio exercises were still needed. • **PAD test for urinary incontinence** – Women who had just given birth, were also accompanied to have a 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. Each woman who has a delivery went through this procedure. 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. <u>HI WASH Strategy:</u> • **HI WASH strategy** – This 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 an alternative approach, to the mindset of supplying everyone with the same, to reach more people but with a more personalized approach.
Successes	<u>Toolkit of protocols and guidance, used at different times over the years:</u> These toolkit items, can be available through this link: https://drive.google.com/drive/folders/1iN06isMpgI9vc6oDeARpHu-u_gjrrGOH?usp=sharing • **Progressive / levelled use of incontinence items in emergency response provision** • **Water cystometry – one channel test** • **PAD test and physio post fistula surgery** • **Comparison tables – catheterisation products –** Overview images of catheterisation products; Comparison table – catheter drainage systems; Comparison table – catheterisation • **Intermittent self-catheterisation instructions**

	• **Product spec examples – tools for hygiene + sanitation –** Bed pan; Handle grip reacher (tool to pick up items from the floor); Hand mirror with handle (to check for bed sores); Long handled brush; Shower stool; Toilet chair; Urinal flash • **Product spec examples – catheterisation –** Catheter bag; Indwelling urinary catheter; Intermittent urinary catheter; Urinary catheter insertion kit; Peniflow bag; Peniflow – uridom (penis sheath) • **Product spec examples – colostomy bags –** Colostomy bag; Colostomy base **Background on the use of the Water cystometry – one channel test** The method was first taught and re-introduced by Pr Wyndeale himself, as a training and practice option for SCI doctors, in a specialized rehabilitation center. Once the practice was described and accepted by the local health authorities, as an alternative to the absence of a Urodynamic system (2–3-way channel), it was introduced in satellite centers (district hospitals and provincial rehabilitation centers). These were selected on the basis of having the minimal requirements (patients in need, trained doctors / nurses who had received training from the specialist center, have the ability to interpret the results, and a safe and clean room, where the procedure can be undertaken). When HI proposed this method as an alternative in other settings, they checked this with technical partners, that were able to fulfil the requirements (such as in Cambodia and Laos).
Challenges	• **Knowledge and developing partnerships and agreements** - HI is not a specialized agency in incontinence and when they worked with universities in Thailand, they also realized, that knowledge on this issue, is not as standardized as we think, Hence, there is a need to develop localized solutions in partnership with authorities and local agencies. They work with the national authorities and consider the risks that they feel are acceptable vs the risks of infection, when selecting options for support (such as the re-use of catheters). In the Syrian context, they developed a ToR, based on their experiences so far, in the far in the South East Asian context and in Haiti they worked with local organisations. • **Challenges related to staff -** There are gaps in availability of certain specialists in HI and not enough available in required timelines in humanitarian responses, including WASH specialists. There are two types of teams in HI: a) **Specialist teams** – who are well trained and know what to do; and b) **Other staff** - who are called on an occasional basis, whoever is available on a particular day to help out, so many of this group are not aware of good practices and protocols. • **Embarrassment talking about incontinence** - People outside of the WASH sector, are not always used, to or comfortable to talk about faeces, urine,

	shit etc. There is also embarrassment of some staff to talk about incontinence. People are not so aware of these issues. So, it would be useful to have sensitization and training days and to open the dialogue on this issue across staff and volunteers.
Opportunities for the future	• **Support an inclusive approach for the whole population** – In a humanitarian context, incontinence is a very basic issue, for which we need to understand the needs in the community and demand. Need to work out what support should be given, to ensure basic needs are met and to adapt this for humanitarian action. The response needs to be very basic, swift and sustainable. • **Considering variations in needs and linking with specialized agencies** – 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. • **Sustainable solutions and not de-skilling** - Need to look for sustainable solutions. Need to provide good patient education and sustainable solutions, and not just give diapers and go away. It is easy 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 some concern over de-skilling people and that no one size fits all. But in acute responses, there is also the need the basics provided, for all who live with this condition. Different kinds of solutions need to be considered, such as urine collectors. In a camp setting, there is a need to deal with some incontinence issues, before they become too big, and to help with physical rehabilitation. • **Educating caregivers and the general public** – 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 a need better awareness in the general public. • **Standards and availability of products** - Need to not copy North American standards exactly, but adapt with regional standards. Look at the products that are available in the local setting and the accepted protocols by local authorities. • **We need to consider broader and more specialized support** – There is a need to support larger numbers of people with more personalized approaches. There is a need to work out how incontinence can be addressed, so everyone has their basic needs for continence supported, as well as supporting the very vulnerable groups of people whose needs are very high and need specialist support. There is a need to consider both urinary and feacal incontinence. There is also a need to work out solutions and get more consensus on the approaches, to be used for different groups of people and people with different kinds of incontinence and due to different causes. They will need to be reached using different channels and

	methods, for example someone with fistula from GBV, this needs to be treated very sensitively and confidentially; someone with a SCI; and someone who is older and has age-related incontinence, will all need contact and support in different ways. • **Working with caregivers and sensitizing staff** - Incontinence needs to be directly addressed, including on the caregiver side and there needs to be sensitization of staff, to be more aware of incontinence and build their confidence to be able to talk about it.

CS-GHA-F - Global – IRC, IFRC – WASH responses supporting children wetting the bed

Focus	**Children wetting the bed due to the trauma of conflict and displacement**
Location	Greece & Honduras humanitarian responses – WASH responses for children wetting the bed
Dates	**Greece** – 2016-2017 **Honduras** – 2020-2021 – in response to hurricanes Eta and Lota
Context	The three examples below, from Greece, Honduras and Iraq, share experiences of humanitarian agencies in providing support for children who were traumatized from conflict or dangerous displacements and who had started wetting the bed. Also see case study **CS-GHA-A** – of the work of Loving Humanity, who also explained the situation in the Syria response in Jordan, which identified that there were also a large number of children who were wetting the bed. And also see the case studies of UNHCR in Syria and of MSF in Iraq, where examples were provided of MHPSS and protection team support related to incontinence.
Activities	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 toilet and hot showers (more than is usually provided in Africa), 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. ○ **Hygiene kiosks** – Many supplies were also donated, including items given from hotels, so they also had 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, they would give it. The taking of products at this stage, was self-regulating, because people were on the move so they only took what they required, to meet immediate needs. • **During the later stages** – ○ **The 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 and was much appreciated.

- **Through this process, the incontinence issue came up** – Children were wetting the bed. They had fled trauma in Syria and faced a hazardous journey in small boats, so they were traumatized. Also, older people and people with disabilities, were are struggling with this issue. People also knew about incontinence products, so knew to ask for them. Whereas, in a country, such as South Sudan, they would not know to ask. At the beginning, IRC did not have products, then they purchased in response to requests.
- **It is very much a dignity issue and bedding was also a major issue** - 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 however, launderettes set up, which again, was not a standard response, but was very helpful.

<u>Greece - IFRC:</u>

- **Justification** - 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 their sheets.
- **People were traumatized when they arrived in Greece** - The teams started documenting the number of people, both adults and children coming forward for support with incontinence. It was the HPs who had this knowledge and identified the problem. They then referred the parents to a doctor, who would then check the problem and issue the vouchers.
- **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 each week. 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 was also a challenge with the collection waste** – This was left out.

<u>Honduras – IFRC:</u>

- **Incontinence had been mentioned in trainings** - But initially, the mistake was made to consider that it was only women of all ages who had this need.
- **They set up a hotline with a Red Cross Volunteer with a mobile phone** – This was so that parents and other people could call to get more soap and pads.

	• **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. This also included mattress protectors.
Successes	• **IFRC** - They did some of the best HP in the Red Cross Movement, in the Greece response. The team has a positive attitude and were open to see new subject they had not worked on before, still 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 issues, so both are needed. • **IRC** - The setting up of hygiene kiosks and hygiene hubs in Greece for people on the move, challenged what is traditionally done in humanitarian contexts. It worked well.  **This was one of the hygiene kiosks set up in Greece by the IRC** (Credit: IRC / Greece / 2016) • The IRC also prepared an excellent Technical Brief[7], on how to set up a Hygiene Kiosk, with lots of practical details included, so that other teams

[7] Lamond, B (2017, draft) *Technical Brief: Hygiene Kiosks; An alternative method of Hygiene Kit Distribution*, IRC

	could follow it step-by-step. This even included floor plans for the kiosk, information on queues, registration documents, record keeping etc. • Plus, following this experience of supporting people with incontinence, they also integrated special needs kits into their Hygiene Promotion Toolkit,[8] although sadly, this element did not gain traction for future emergencies.
Challenges	• **IRC** - However, even though the hygiene hubs and hygiene kiosks worked well in Greece, it proved more difficult when trying to replicate them in other countries. This was tried in Nigeria, but was not successful. • **IFRC** – The team found it difficult to get approval from their managers to support incontinence issues, as they didn't see it as their responsibility. • **IFRC** - Women were used to bleeding, so they had the experience of using cloths and hence this made it more difficult to use what was provided. Sizing was also a challenge, as in the emergency they distributed 200 small and 600 medium sized incontinence pad packs. • **IFRC** - They also realized, that it was more difficult for children and adolescents to request support for incontinence, than adults.
Opportunities for the future	• The hygiene hub and hygiene kiosk system, set up outside the female toilets, worked well in Greece, so it should have the possibility to also be adapted to other contexts, and can allow the choice of hygiene items, including incontinence products, which also offers more dignity to the process. But practical challenges, such as security of kiosk stock, and the team's familiarity with established NFI kit distribution processes, meant it was not as successful in being set up in other contexts. • The testing of different methods, such as the use of the phone line, using the doctors to screen the need for support and the voucher systems, offered useful learning for the kinds of methods that could be used to support people living with incontinence. • The provision of showers and laundry rooms, were positive developments for the refugees, but are not usually provided. There is also a clear imbalance between what was provided in the European emergency and what is provided in other parts of the world, which also poses ethical challenges for the humanitarian community. • In both Greece and Honduras, the IFRC also supported health facilities in the camps, which also offers the opportunity for engagement across sectors.

[8] Klaesener Metzener, N, Mathenge, P and Walker, L (no date) *Hygiene Promotion, Sector Toolkits for Emergency Programs*, IRC

CS-GHA-G - Global – MSF – Integrating incontinence into health responses

Focus	**Integrating incontinence into health responses**
Location	**Global**
Dates	On-going
Context	MSF is an international, medical humanitarian organisation, working in more than 90 countries around the world, working in conflict zones, natural disasters and epidemics. This case study shares observations and thoughts of a number of professionals working in MSF, including some of whom have previously worked for other organisations, in how people with incontinence engage with health organisations and are supported in their incontinence and the current issues and gaps. It is hoped that this case study, will also encourage more self-reflection from other health sector actors, in how the sector can better support people with incontinence through their work.
Activities	<u>MSF incontinence-related activities:</u> • **MSF engagement with incontinence** - 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. But teams have seen a range of examples of people with incontinence through their work. For example, people with learning difficulties and elderly people. Patients with prostrate 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 and older people are often unseen, except for occasional examples, such as an elderly gentleman, who used to come in for intermittent catheterization support in Darfur. • **MSF fistula activities** – 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 stench they are spreading 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 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. Reasons: OF is not a life-threatening condition and MSF prioritizes reducing directly life-threatening conditions and on increasing access to care (hence there are also budgeting priorities); challenges to maintain a pool of well-trained fistula surgeons; workload of already overburdened teams, this has implications when organizing an OF campaign, which is (by definition) an 'add-on' to existing MSF emergency obstetric care programs. <u>Challenges/barriers for MSF organizationally:</u> • **People with incontinence – not yet seen as a core commitment** - People with incontinence are not yet common populations seen in MSF and are not mentioned in documents. For medical doctors, it is generally not seen as a core commitment – it is seen as a nurse's responsibility. It is considered that it should only be carried by nurses, but it also needs to be embraced by doctors. • **Difficulties engaging across sectors** – The same as in other organisations, there are also challenges for working across different health teams. Reflection is usually in siloes, so there is often a lack of multi-disciplinary work. • **Use medical lens and gaps in wider focus** - Some countries [outside of MSF], often have incontinence nurse specialists and there is a need for physios and other health professions, such as occupational specialists and mental health specialists, to work on these issues in health services. But a lot of planning in MSF is medical focused and we don't see the wider picture – we miss the "multidisciplinary team lens". There is a need in shift of mindset, from the medical focus to a broader health focus. • **Getting incontinence products into the catalogue** - It took many years to get the incontinence items such as pads, incontinence pads (nappies) and incontinence sheets into the MSF catalogue. Previously, it was seen as not being an essential health or humanitarian item, but now we have some adult incontinence products in the catalogue.
Successes	• Have incontinence related products into the emergency supply catalogue • Support for obstetric fistula and fistula as a result of GBV in some locations • Some support for people with traumatic war injuries, with stoma bags

Challenges	<u>Observations and learning on practical needs and challenges in health-care settings:</u> • **There is limited access to incontinence nurse specialists** – They have more knowledge and experience of supporting people living with incontinence and how to care for them most effectively. • **Mattresses and beds** – There are challenges from how they are made. It is shameful to soil your bed and directly on the mattress, but it is difficult to know when patients arrive, if they may soil the mattress. It is also easier for parents to admit this issue about their children, than for adults. In some places it is standard to have an incontinence (draw) sheet and protection, so that even if a person does not share that they may soil the bed on day one, it will still be protected and less shameful for the person. It would make sense to make sure that all beds automatically have a protective cover. The mattress protectors / incontinence sheets, have different names – in some places it is known as a 'bluey', inco, or drawsheet, which confuses supply ordering. • **Limited privacy in hospital settings** – It is a very personal thing, going to the toilet, but in some emergencies e.g. for cholera responses, people are left lying down with their faeces / diarrhoea pouring openly into a bucket under the bed, in full view of the next patients. • **Sometimes there is overuse of invasive incontinence tools and products** – There can tend to be an over catheterization of people, because of not having enough nursing staff, or not enough privacy to go to the toilet, or unable to access the toilet (distance or not enough). So, they end up inserting catheters, leading to increased risks of infections. Have had an example in a programme, where the teams were asking for the condom catheter (this goes on the penis, and feeds into a tube and a urine bag), as the team did not have time to bring the person to the toilet and incontinence sheets were not available, or adult incontinence underwear/diapers. • **Challenges with language and how to talk about this issue** - We are not clear on the language to use and not confident in spectrum of leakage. How do we consider and talk about the spectrum of incontinence? For example, if someone wants to talk about a wet fart (where you release air, but also faeces come out), how do you put this into words? Also, is a little streak in your pants, an important issue? How do we understand what is a major stress for a person and the mental health impacts? People may have fear, anxiety and high rates of depression. • **People do not feel comfortable to ask someone for help, even with significant challenges in their lives** – For example, a woman may not want sex with their husband, because of leakage they feel uncomfortable to. • **Males may be more reticent to come forward** - Males who have incontinence around prostrate problems, may also not feel comfortable coming forward and they may also have a lack of awareness on this issue.

	• **Nurses may also be reticent to support patients** - At the moment, we often delegate toileting care to caregivers, as we don't have time as nurses. Some nurses also do not want to do this, with many reasons given about workforce / human resources, not being sufficient. There is also almost a stigma even in the sector, to deal with incontinence and it is a taboo subject. • **Skin assessments need more priority** - This is an area that needs more attention and assessment tools, as patients can deteriorate quickly if they have problems with the skin. This needs more accountability from nurses for this issue, but we also recognise that patient numbers also tend to be high, so time availability, is also challenging. • **Barrier creams** - Moisture lesions are particularly difficult and pressure sores can be fatal, so there is a need for something simple and effective. But barrier cream, is not in the MSF catalogue. There are also challenges with adhesives, bandages, tapes. So, we sometimes have to ask *'what do mums put on babies bottoms locally?',* such as oils or butter? This is so that people can use this, if they have no access or ability to get other creams. • **Mental health challenges** - This issue is so important – it is like a vicious cycle – leading to mental health issues and stigma. For example, in a family of five people, there may be 2 of the 5, who have incontinence problems and there can be huge issues of domestic abuse and violence in the family. Stigma can also be associated with emotional or traumatic events and is quite high for females – for married women and children. For the mental health component, this is sometimes not prioritized. For example, if there is a malaria peak, then we would not encourage parents to bring their children who are bed wetting into the facility and we already do a vast amount in the PHCs, focusing on the main morbidities (e.g. malaria, diarrhoea, malnutrition, pneumonia). • **Pelvic floor exercises** - MSF have a pelvic floor resource in their library, but MSF is not an expert organisation in continence issues, or the pelvic floor exercises. The physios focus more on post traumatic injuries. It is not dangerous to do pelvic floor exercises, it just won't be useful for all people, such as if they have had too many children, or have a lot of damage from a heavy labour. This should also be helpful for people after hernia surgery, to strengthen the muscles again and also helpful for men. The big challenge is convincing women to keep going and doing it for weeks, or months several times a day.
Opportunities for the future	• **Progress in MHM** - In MSF, there is a lot of enthusiasm for trying to move this forward. There has been quite a lot of progress on MHM, so it is hoped the same will happen with incontinence. MSF has been including MHM items in distributions, have provided special toilets for MHM management. • **It is hoped that incontinence items can also be added to distributions** - Although it is more difficult to identify people to give additional NFIs to for

	incontinence, so ways need to be identified to encourage people to come forward. • **MSF catalogue and items purchased in country** - Make sure that all beds automatically have a protective cover and add barrier cream options. • **School nurses would be valuable to strengthen support for this issue and deal with this all the time** – We should reach out to them. MSF works mainly in PHC and OPD – the work has not been taken to people in schools our other places outside of the facility. • **Raise awareness and increase visibility on this issue across sectors** – To continue with the start that has already been made to raise awareness within MSF and trying to increase more visibility on this topic. More efforts needed to encourage doctors to also take responsibility for incontinence and not only leaving it up to nurses and to strengthen cross-team / specialism working. • **Work one step at a time** –Include questions in the nursing assessment, without making people uncomfortable, so at least someone is aware. To continue to look at strengthening the Nursing Admission Assessment process, to cover people's abilities to wash or toilet themselves. • **Need more tools on skin assessments, and to recognise how quickly patients deteriorate** – Nurses need more accountability, for supporting patients with this issue. • **Incorporate on safeguarding** - There is a need to be more person-centered in our responses and to link this in with MSFs ambitions to also acknowledge the importance of safeguarding. • **Doing pelvic floor exercises could be useful** – Could do in peer groups as group exercises. This is what was found useful, in relation to fistula clinics. • **Strengthen focus on mental health around fistula** - There has tended to be a focus on the role of the surgeon for fistula, but it would be good if someone around deals with mental health. There needs to be an atmosphere where women ambassadors, who have been operated on before can provide support to other women – this has been done before and has helped.

CS-GHA-H - Global – UNFPA, MSF, partners – Fistula prevention & response

Focus	**UNFPA, MSF, partners – Fistula prevention & response**
Location	**Multiple countries with fistula hospitals and surgery**
Dates	1997 – to-date See also **Section 5.1.4** and **Annex III.2** – on ELHRA/HIF funded research led by ReGIG on the WASH needs of women with fistula in Ghana; and **Case study CS-GHA-E** – on HI work with people with spinal cord injuries, which also includes a section on fistula.
Context	**UNFPA** UNFPA works at global, regional and national levels, to promote universal access to sexual and reproductive health care and rights, including by promoting international maternal health standards and providing guidance and support to health systems. UNFPA-supported programmes, emphasize capacity development in maternal care, especially through strengthening of health systems, human resources, and for respectful and human-centered quality care. UNFPA focuses on 32 countries with poor maternal health indicators, through its **Maternal and Newborn Health Thematic Fund Programme,** through four pillars of 1) Prevention and response to obstetric fistula, 2) Strengthening midwifery, 3) Strengthening Emergency Obstetric and Newborn care, and 4) Enhancing Maternal Perinatal Death Surveillance and Response. UNFPA's work spans both humanitarian and development contexts. UNFPA's maternal health and thematic fund program, is also implemented in a number of countries which have humanitarian crises, including but not limited to, Bangladesh, Somalia, Sudan, Nigeria, DRC and Mozambique. **Obstetric, GBV-related fistula** This occurs as a result of obstructed labour, leaving the woman with incontinence, (leaking urine or faeces or both), with other severe medical, psychological, social and economic consequences. Obstructed labour can also occur during crisis situations, leading to fistula and needs to be addressed accordingly. Gender based violence, including rape, which is usually exacerbated in crisis situations, can also result in fistula (often referred to as "traumatic fistula"), and Iatrogenic fistula – fistula which occurs as a result of a medical mishap – usually occurs during Caesarian sections and hysterectomies. Fistula is globally recognized as a public health, development and human rights issue. Women and girls have a right to essential maternal health and sexual reproductive health services, and also have the right to safe surgery, including caesarean sections and fistula repair surgery.

Activities	**UNFPA:** • **UNFPA's approach to obstetric fistula -** UNFPA's Obstetric fistula prevention and response, seeks to strengthen national capacities to prevent and respond to obstetric fistula, using a health-systems strengthening approach to address the supply side of services. They work with both the duty bearers and rights holders. UNFPA provides technical guidance and strategic direction to inform programme development and implementation. It works from global to ground levels, on good practices and influencing policies in countries. • **UNFPA's priorities for humanitarian contexts** – These are getting national ownership and development and implementation of national strategies to prevent maternal mortality and morbidity and monitoring. As well as engaging with partners, to strengthen synergies and utilize comparative advantages for shared goals. **Campaign to End Fistula and UNFPA's role:** • In 2003, UNFPA and partners launched the Campaign to End Fistula, to raise awareness of obstetric fistula, as a severely neglected health and human rights tragedy. This global initiative, is led and coordinated by UNFPA with the aims to make obstetric fistula, as rare in developing countries, as it is in the industrialized world. The Campaign brings together hundreds of partner agencies at the global, community and national levels, and is present in over 55 countries across Africa, Asia, the Arab States and Latin America. There are around 100 partners globally and many other at country levels – government, NGOs, health facilities. • UNFPA/Campaign to End Fistula, focuses on a four-pronged strategy of: Prevention, Treatment, Social Reintegration and Advocacy. • UNFPA provides strategic vision, technical guidance and support, medical supplies, training and capacity building, as well as financial support for fistula prevention, treatment and social reintegration programmes. UNFPA also strengthens sexual and reproductive health care and emergency obstetric services as preventive measures. • UNFPA supports the development and implementation of national strategies for fistula prevention and response. This ensures country ownership and sustainability of efforts to end fistula. They also encourage governments to establish functioning national task teams, to monitor and coordinate in country fistula prevention and response, including government, NGOs and fistula surgeons. Capacity building and strengthening health systems for preventing fistula and treating it, also contributes to improve maternal health outcomes and reduce mortality. All women and girls have a right to receive timely, quality care to prevent fistula (not just those who reach the health facility).

	• Women and girls who reach the health facility have a right to get timely quality care to prevent obstetric fistula. **Identification of clients:** • In countries, they work with Ministries of Gender, Health, or Non-governmental organisations and CSOs to identify clients for treatment. Clients are usually poor, illiterate women in remote locations, who may find it difficult to access treatment. • They work on surveillance to prevent fistula and they educate providers on how to identify clients and establish a coordination and referral system in place, for clients to be identified and referred for treatment and support. **Fistula care:** • This addresses the supply side of the health system, through strengthening the staff side – developing the skills of surgeons and ensuring women get access to treatment. They focus on quality of care – surgical and non-surgical. • Fistula care needs to be for the whole person – to provide support for the social and spiritual sides, as well as the fistula itself. • Social reintegration is part of a holistic approach that addresses the psychological and socioeconomic needs of fistula survivors. Interventions provided by UNFPA and partners, include but are not limited to, psychosocial counselling, education on sexual reproductive health, income-generating skills, links to support groups and small-scale businesses and starter packs for a business. Some fistula survivors are also empowered as advocates against fistula and as Safe Motherhood Ambassadors. Follow-up on fistula survivors after treatment, is also key to their well-being. • Social reintegration of survivors, together with interventions, to demystify the condition and reduce stigma, contribute to restoring the dignity of fistula survivors. • Unfortunately, some fistula survivors, suffer such extensive, severe injury that they are deemed inoperable, or incurable and may not have total healing (even after multiple fistula repair surgeries) and may still leak. These survivors, face additional challenges and should be provided social reintegration support as per their needs too. **Development of a community-based assessment tool for obstetric fistula -** • 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, WADADIA - Habiba Mohamed, Yussuf Omenda, Lindsey Pollaczek (2015) *Obstetric Fistula Community Based Assessment Tool (OF-COMBAT), International Journal of Recent Research in Social Sciences and Humanities (IJRRSSH),* Vol. 2, Issue 4, pp: (127-133), Month: October - December 2015,

	https://www.paperpublications.org/upload/book/Obstetric%20Fistula%20Community-544.pdf **Materials for managing fistula -** • The idea of continence products, has been discussed for years and in India they considered bamboo products, but these were not appropriate. Continence products need to be affordable long term. There has not been much focus on re-usable pads or underwear. • People are spending so much money on diapers, but it is not sustainable, so they need income generation support as well *"We also had the same experience… that fistula survivors (most of whom were already quite poor), were spending a catastrophic amount of money on diapers, sometimes at the expense of feeding their children adequately, paying school fees, etc"* (SRH humanitarian actor) • There are also urethral plugs, for use after fistula surgery and catheters are also used in fistula care • Pelvic floor exercises – Kegels can be done even on a bus • There has been some discussion on the use of menstrual cups for urinary incontinence, but although there was some research undertaken on this topic in Ghana, there is not insufficient evidence at that time, to lead to policy or programme changes. **Examples, with countries with high caseloads of fistula** - • Northern Nigeria has some of the highest fistula cases in the world • Ethiopia, Bangladesh, Somalia, Tanzania
Successes	• See above – there have been multiple successes, such as the development of the Global Campaign, training, update of the UNFPA, "Orange manual", many surgeries, etc.
Challenges	**Fistula and other post-partum incontinence related challenges -** • 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 a huge three- dimensional injury. The bigger damage comes from longer obstruction in delivery, where it takes a longer time • 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 surgery[9]. • There are also hidden connections to other forms of incontinence, leaving women very miserable, but they are portrayed as a happy lady afterwards holding a baby. But it is not so infrequent, that it works out this way, that the women still have incontinence after the operation. 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 have been just as wet as they were. 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. • It is unknown how many more women have died because of uterus rupture on labour, as they may have died in their dwellings, as well as high numbers of women who face incontinence post-partum. For most, post-partum incontinence is temporary[10]. • 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, as they may have had these issues before, but the problems become worse after more births. • There is also broader maternal morbidity which also occurs – such as prolapse of uterus, mental health/psychosocial problems, sexual dysfunction, infertility, etc. • Also, for example, in Nigeria, and many other countries where fistula occurs, this is also seen as a taboo, with the victim smelling badly from the constant flow or urine or faeces. 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 **Challenges with fistula surgery and fistula care** - • Some women have a hysterectomy and a nick happens in the bladder or bowel and they get urinary or feacal incontinence, so there is a need for the building of safe surgery skills. There tends to be more focus on the surgery component than the others.

[9] Nardos R, Jacobson L, Garg B, et al. (2022) Characterizing persistent urinary incontinence after successful fistula closure: the Uganda experience. Am J Obstet Gynecol 2022;227:70.e1-9https://www.sciencedirect.com/science/article/pii/S0002937822001788

[10] For data on maternal mortality: https://www.who.int/news-room/fact-sheets/detail/maternal-mortality

	• Want to learn how to do urinary diversions, but has to be appropriate and life-long care, as women can end up dying of this. Some women may need this, but it is too challenging to do, with the on-going care. • In the beginning, most surgeons doing repairs were Gynecologists, but had no real training, as it was felt to be very straight-forward for staff. Many doctors, even Obstetricians and Gynecologists (OBGYNs), don't have surgical skill sets and are potentially doing more harm than good to women/girls suffering from fistula. We need to establish if preventing fistula is part of the curriculum? Even in high income countries? • In general, hospitals just want to have the surgery be done by a physician and not consider the woman/girls' wider needs. • So, the way fistula is handled is a: *"Public health issue, in a surgical sandwich".* • Training is being done for public health graded clinicians, with a weekend seminar, but what is really needed are adequate surgical/medical/clinical education, plus mentorships for years to pass these skills along. • Need public health doctors in continence care, that have the background and equipment to do this. Consolidation is needed, even most conflict-affected cities, there are a few people networked and facilitated and enthusiastic, who can handle this in practice, so capacity building / mentoring support is needed. • There needs to be a team of professionals for support, including specialists with gynecology, urology and social services externally. There needs to be one-stop shopping, not to have to go to one place for different specialists – nurses, urodynamic, physios and dietician, social workers and/or mental health care professionals. • Urodynamic studies, are also very expensive and can cost around USD 20,000. But hospitals may only have USD 200 per woman, so decisions need to be made on how to use the resources. There are some simpler urodynamic studies, using a catheter and a syringe, where they are repeated after a year. • Covid also impacted a lot on women's ability to get fistula operations. **Challenges for the global campaign** - • Fistula is considered a rare condition, so the numbers are relatively not so large and as we get better at demographic science and fistula estimates go downwards, which also means that this subject gets less attention and resources • Most often it happens to adolescent girls in the poorest countries, but it is not limited to adolescents (though this is a misconception that people sometimes have). It also causes disability. Maybe it needs to link it into other issues, to get higher attention on it, rather than as a stand-alone issue? • Efforts are being made to integrate it into global maternal and newborn health and linking it with maternal and pre-natal deaths. When a woman gets

	fistula, it means the woman or baby were near death and can also mean they continue to struggle so much, and can still lead to new-born deaths. • Efforts have also been made through the UNFPA/Campaign to End Fistula, to integrate fistula into global and country-level work on disabilities, human rights, gender equality, etc. And also, through UNHCR, efforts are being made to integrate it into broader health, protection, WASH & other sectors.
Opportunities for the future	**Key actors in fistula care** - • **Dr Steve Arrowsmith** - Has been supporting Fistula Surgery Fellowships, so that each country has more trained fistula surgeons. Ideally, each country really needs skilled surgeons, who are urologists, plastic surgeons etc. to be based in National Teaching Hospitals. • **USAID has funded a global fistula care projec**t - 5 year. This includes prolapse and fistula care and also includes analysis of the fistula situation and efforts to integrate this issue into maternal and newborn health. • **CCBRT in Tanzania** – Has developed a model of Community Ambassadors in villages. They have established a partnership with a mobile phone company, so that if they found someone, they could use screening tools and if women have fistula, they could use money from the phone system, to bring people into hospital for assessment / surgery. • **WHO partnership** – They have been doing some studies on whether catheterization of women after fistula surgery, can be done just for 7 days instead of 14 days and have been findings so far, that it can be just as good. This means they spend less time in hospital which is less cost. They have developed and published guidelines: https://www.who.int/publications/i/item/9789241550192 • **Hope Hospital** (in Cox's Bazar, Bangladesh) – Ethiopia - Has 'Healing Hands of Joy" – Community Ambassadors. • **International Confederation of Midwives** • **Direct Relief** – Focusses on materials for healthcare • **Fistula Foundation** – a private charity for fistula repairs • **Direct Relief and UNFPA prepared a Global Fistula Map** – where the fistula centers are: https://www.globalfistulahub.org/ **Fistula events** - • There is a UN Session on Ending Obstetric Fistula every few (two) years, which has the mandate, under the UN General Assembly on ending fistula. The UN Secretary General publishes a report every 2 years, on ending fistula and the UN General Assembly, typically adopts a Resolution (on the basis of that report), on ending fistula every two years. • There is an International Society of Fistula Surgeons – which meets every 2 years

	• There is an International Maternal and Newborn Health Conference • There is also an International Conference of Midwives – every 3 years • International Day to End Obstetric Fistula – every year on 23rd May. This is an official UN international day. **Guidance -** • The UNFPA (2021) *Obstetric Fistula & Other Forms of Female Genital Fistula: Guiding Principles for Clinical Management and Programme Development*, also known as the "Orange manual" It has different chapters – including on the pelvic floor and a chapter on physio - UN global guidance on ending fistula • WHO recommendation on the length of bladder catheterization following surgical repair of a simple obstetric urinary fistula (2018) • DHS analysis of incontinence data (2008)

CS-GHA-I – Global – UNICEF, WHO - Supply and innovation – including in Ukraine

Focus	**Identification and innovation for incontinence-related products and supply to Ukraine**
Location	**Global & Ukraine:** • **UNICEF, Product Innovation Centre, UNICEF Supply Division** • **WHO, Access to Assistive Technology (ATA) Team, Medical and Health Products**
Dates	Products supplied from UNICEF to Ukraine, 2022 MOOC on absorbent products opened up for participants, 2022
Context	<u>WHO and UNICEF:</u> UNICEF and WHO tender together. WHO programmes do not have big procurement like UNICEF, but instead are normative, i.e. they establish the norms and standards. <u>UNICEF, Product Innovation Centre:</u> UNICEF procures a large volume of products, which are of value of approximately USD 7.2 billion / year. Most of this is spent through the UN family, but some is procured on behalf of governments and other partners. Copenhagen, the Supply Division, has 500-550 staff. UNICEF country offices and WHO, also identify the highest needs for products and WHO and UNICEF identify primary products and needs in daily life and establishing a priority list. As part of work to increase global access to assistive products, they use tendering, as part of a toolbox of approaches, to get the best brands. This increases competition and the quality of products. If a product exists, then the team looks at others and see the market status. If there is enough competition, with other manufacturers, they then they do a tendering process, and they tender for 10-15 products. Manufacturers compete for long-term agreements (LTA) agreements, which are 2-year contracts, which are not binding to sell or buy and there is usually more than one. When suppliers sign an LTA, then the products go into the UNICEF supply catalogue. The next phase, is then to advocate for products and use through UNICEF and other agencies. The project then starts scaling. NGOs, academics, other agencies, and governments, can also use the procurement service. This system is particularly useful for governments, as they can procure large volumes of items at a reduced price and have local knowledge and can manage freight and customs. The items are sold on a non-profit basis, except for a fee of 3-4% the total value, added to the costs of managing

	procurement, except for government and UN agencies, who do not pay this fee. The procurement system, is mainly used for vaccines. WHO, Access to Assistive Technology (ATA) Team, Medical and Health Products: The ATA team receive priorities for assistive technologies and provide guidance to member states and support member states which are struggling. WHO's role is the development of normative documents and assistive products list, and the development of tools and resources. They work through regional advisors and some links to countries and some WHO Directors. Plus, they undertake some pilots, activities and support some technologies. They are involved in policy, strategy; training personnel; operation and maintenance; understanding and supporting ecosystems; and identify use of the products. They also devise and run trainings.
Activities	Agreement between WHO and UNICEF to work together on incontinence: • GATE in WHO and UNICEF, have a director level agreement to work together on incontinence. Discussions between the two agencies, have mainly been focusing on products and inputs to list and access to research, so they can work out products and suppliers and to work on incontinence. UNICEF, Product Innovation Centre: • **Strengthening access to assistive aids** – UNICEF is working to ensure assistive and inclusive supplies are affordable, quality and accessible worldwide, including 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 do scale -up projects, for products in high demand with incontinence, inclusive education products, Digital AT and vision products, which are 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. • The Supply Division, Product Innovation Centre, is working on a number of WASH-focused products, including in the Emergency Challenges team. For example, Esther Shaylor, has been focusing on two accessible latrines, to help promote inclusive education. Muhidin Abdulla, is leading work to identify incontinence products. They are also working on women's products and hearing aids. • **UNICEF Product List: Assistive Technology and other relevant products for children and people with disabilities in emergencies**: 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

	• **Coordinating an incontinence kit** - Incontinence products are seen as niche products and are not widely available and competition is not as strong as we would like. Muhidin has been coordinating a kit, not only for UNICEF use. There is currently a list of many products – 13 in the draft list, which is currently still in an early stage. These products will be reviewed, based on experience and consultations, and then will be taken further, over different options for WASH products. Muhidin, had initial support and advice from the informal email group on incontinence, and a list has been identified, at this stage which includes: Diapers; Underwear; Hand held urinal / Urine collection; Pull pads; Night pads; Soft cotton material; Absorbents; Bottom wipes; and a Pad for mattresses. • **Hygiene kits for people with special needs in Ukraine** - In addition, some items have already been included in hygiene kits, through including small hygiene kits for people with disabilities in Ukraine. There are four items in the kits, including diapers, mainly for older people and adolescents. Huge numbers were requested and sent, as part of disability emergency planning for Ukraine, with a UNICEF WASH Officer ordering the kits. 38,000 hygiene kits have been sent to Ukraine for people with disabilities for children and adolescents with disabilities. The UNICEF Country Office, with one or more implementing partner, will do the distribution in Ukraine. But at this stage, no updates are available, as to how many have been distributed, or any learning from this process. • **Disability – designing accessible toilet slabs** - A research project is also 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 done, by including 10% of the slabs sent to humanitarian contexts, with the add-ons. At the moment there is only one solution, which is related to kits to attach to latrine slabs: One kind – fits on slabs during construction, and the other can be fitted over an existing toilet slab. One is more expensive for shipping and the other is cheaper. The more volume requested, the cheaper the product becomes. They are currently in the process of scaling them and there is now a need to increase the uptake of products. The need is there, but they need to encourage people to demand these products and to prioritize them for funding. They don't have LTA yet for toilet chairs, but they have included them in existing product tenders, for the supplier of wheelchairs. <u>WHO, Access to Assistive Technology (ATA) Team, Medical and Health Products:</u> • **Considering incontinence** - More health workers are having the conversation and helping people to get to toilet and to urinate and how to deal with difficult continence issues at night. Training for Assistive Products (TAP) team, is thinking about this and how to talk about this issue. • **There are currently 6 products in the APL lists** – These are linked to the Washington Group questions. Incontinence fits in the self-care question. The

items included are: shower chair, toilet chair, absorbent products and catheters.

- **Priority assistive products lists** (APL) - They help to develop these items to be the best they can be, by developing normative descriptions. The Priority Assistive Products List, includes hearing aids, wheelchairs, communication aids, spectacles, artificial limbs, pill organizers, memory aids and other essential items for many older people and people with disabilities, to be able to live a healthy, productive and dignified life. 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 also argue for other areas 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 chair, not for personal use [for hospital use]. The broader list goes to absorbent single use products in medical facilities. Plus, it includes assisted products used by the MoH, for people who are displaced within a country, includes catheters and absorbent products.
    - DG Catheter list - Innovation being undertaken by Australia for this list, after a lot of research, with self-intermittent catheters.
    - Medical list – It is not clear if mattress protectors are in the medical kits.
- **Assisted products specifications** – This includes the specifications for 26 of 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 has been prepared, including an Absorbent Products Module. A launch occurred in Nov 2022, and thereafter, the training will 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 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 to the products have been made for the Ukraine contexts. This includes adding self-lubricating catheters for the kits 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, evaluation and learning activities, are planned for the end of the process. • **GATE initiative** – This aims to improve access to high-quality affordable assistive products globally. To achieve this, the GATE initiative focusses on interlinked areas (5P): people, policy, products, provision and personnel. '*WHO is developing tools to support countries in developing national policy and programmes to ensure everyone, everywhere can access assistive products. The toolkit will include an assistive technology assessment toolkit and guidance on financing mechanisms, such as health and welfare insurance programmes, to ensure sustainability of service provision and universal access. It will also include guidance on implementation of the Priority Assistive Products List, minimum standards, appropriate training and service provision*' – Previously sourced at: https://www.who.int/news-room/feature-stories/detail/global-cooperation-on-assistive-technology-(gate) <u>Supporting links:</u> • **Global Report on Assistive Technologies –** WHO - https://www.who.int/publications/i/item/9789240049451 • **Priority Assistive Products List 2016** - https://apps.who.int/iris/bitstream/handle/10665/207694/WHO_EMP_PHI_2016.01_eng.pdf • https://www.who.int/news-room/feature-stories/detail/priority-assistive-products-list-(apl)
Successes	• Multiple successes, as documented above, in raising incontinence higher on the agenda. • Including incontinence-related products in NFIs kits, including large numbers sent to Ukraine by UNICEF, as well as the trials in Ukraine being supported by WHO in 10 health care facilities. • Continue to develop and test the more detailed incontinence product list and roll out its use in emergencies. • The development of the adapted toilet chair options and testing in the field. • The development of the MOOC for absorbent products.
Challenges	<u>UNICEF, Product Innovation Centre:</u> • Some challenges are being faced with scaling the use of the adapted latrine slabs, because even with the accessible toilet slabs, some people still cannot reach the latrines, because of the access to them, such as when they are at the top of a hill.

	• Another challenge, is that there are many different people working in countries and programmes and they don't know about this issue or the need or availability of these products, so the supply team don't often get requests. There is a need more capacity and knowledge on these areas. WHO, Access to Assistive Technology (ATA) Team, Medical and Health Products: • One challenge for assistive devises, is that they are needed across departments – cross-sectional - age, children, adults, people with NTDs. They are not just under rehabilitation. It depends on the context – how much freedom there is to collaborate.
Opportunities for the future	• To learn from the UNICEF and WHO efforts in Ukraine, for future responses. • To continue to build on the progress made so far, in incorporating incontinence-related items into the APLs. • There is a need to keep collaborating across UN agencies and also with NGOs and governments. There is a need to ensure consistency and reduce competition between agencies, so that countries do not get confused. • If countries are developing TAP lists, it is important to feed in, in relation to items to support incontinence and also to integrate their use into policy. • WHO has a process to develop guidelines materials on specific issues. For this they need a stakeholder group and a member state to request it is prepared - https://www.who.int/publications/who-guidelines