

# INCONTINENCE MANAGEMENT TRAINING FOR HUMANITARIAN PRACTITIONERS

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### **ACRONYMS**

KII Key Informant Interviews

MANEPO Malawi Network of Older People's Organisations

NCA Norwegian Church Aid

NGO Non-Governmental Organisation

ReGIG Research and Grant Institute of Ghana

UN United Nations

WASH Water, Sanitation and Hygiene

WHO World Health Organization

### **EXECUTIVE SUMMARY**



Incontinence—the inability to control urination or bowel movements—is a significant medical and social issue affecting individuals across all age groups, particularly older adults and their caregivers. It presents unique physical, emotional, and psychological challenges, which are exacerbated in humanitarian contexts where resources and support systems are often limited. Despite being recognised as a global health concern, incontinence remains under addressed within key humanitarian sectors, including health, protection, and water, sanitation, and hygiene (WASH). Stigma surrounding the condition further complicates identification and assistance for those affected.

In response, Oxfam, in partnership with HelpAge International and the Malawi Network of Older People's Organisations (MANEPO), and with funding from Elrha, has developed a comprehensive incontinence management package. This initiative seeks to empower older individuals and their caregivers with practical tools to manage incontinence during crises while enhancing the capacity of humanitarian practitioners to provide dignified and effective support. Central to this effort is practitioner training in incontinence management, aimed at equipping responders with the skills and understanding necessary to address the condition sensitively and effectively.

The incontinence management package is designed to:

- Raise awareness of incontinence as a critical issue in humanitarian responses.
- Reduce stigma by fostering open dialogue and understanding about the condition.
- Provide practical solutions that empower affected individuals and caregivers to actively manage their needs.
- **Enhance practitioner skills** through targeted training, ensuring support is empathetic, informed, and tailored to individual requirements.

This case study focuses on the implementation of practitioner training in Malawi, using this context as a proof of concept for the innovation. Evidence from Malawi indicates that **the training is driving meaningful improvements in incontinence care in humanitarian settings**. Practitioners trained in the programme have reported greater confidence and capacity to better support those affected. Furthermore, early outcomes suggest progress in reducing stigma around incontinence, creating an environment where the condition can be discussed openly, and those impacted feel empowered to seek care with dignity. **The training is projected to reach over 200 practitioners in 11 contexts by the end of the project period.** 

The innovation journey of the incontinence management package reveals critical insights into the challenges and opportunities of implementing new solutions in humanitarian contexts, including:

- Cultural and contextual adaptability are crucial but require time to develop. Elrha's sustained long-term
  funding has allowed the participating organisations to gain a deep understanding of incontinence across
  diverse populations and settings. This comprehensive insight has been leveraged to create an evidencebased training programme that prioritises sensitive, inclusive, and dignified approaches to supporting
  individuals living with incontinence.
- **Securing government and organisational buy-in** is equally essential. Strong leadership and policy support, as demonstrated in Malawi, are pivotal in driving meaningful change and ensuring long-term assistance for those affected by incontinence. Without such commitment, progress is likely to stall, and practitioners may struggle to effectively apply their knowledge and skills.

More detailed data on the effectiveness of this innovation is expected to be available in 2025.

### **INTRODUCTION**



#### What is incontinence?

Incontinence is the inability to control urination or bowel movements. This means a person may accidentally leak urine or faeces, which can affect people of any age but is more common in older adults. It can be caused by medical conditions, physical changes or stress and often requires special care and support to manage.

Incontinence is a significant global health issue affecting people of all ages and genders. It presents several negative challenges around mental and physical health, finance, hygiene and practicality for people living with it and their caregivers, who also experience emotional and social challenges arising from stigma as incontinence remains a taboo subject in most contexts. Despite evidence of these challenges, people living with incontinence, their caregivers and humanitarian practitioners have limited knowledge of treatment options and solutions to manage it. 2

To address these challenges, Elrha has funded a series of projects along the <u>innovation process</u>, supporting studies to understand the problem better, developing, piloting and rolling out training for WASH, protection and health practitioners on incontinence management. Since 2023, Oxfam, HelpAge International and MANEPO received funding to develop a more comprehensive incontinence management package. This package aims to give older people and their caregivers more control over the dignified management of their incontinence during humanitarian crises and be better supported by WASH and other actors. The package has four components:

- 1. A practical home-based care training package for people with incontinence.
- 2. Comprehensive feedback from older people and their caregivers about the most appropriate items for managing incontinence based on context.
- 3. A uniform set of 'Washington Group' style questions tested across 11 contexts, which can be routinely incorporated into humanitarian surveys and discussions to better assess the prevalence and severity of incontinence in emergency situations.
- 4. An updated version of the training for humanitarian practitioners on incontinence management rolled out in 11 countries.

This case study focuses on the training for humanitarian practitioners on incontinence management in Malawi as this is the most advanced element of the package. At the time of writing this case study, the project has been rolled out in Malawi, Yemen, Lebanon, Ukraine and South Sudan, and will be rolled out in six other countries<sup>3</sup> in 2024. In Malawi, the training took place in November 2023 and MANEPO facilitated a refresher training in August 2024.

Whilst the humanitarian practitioners training is the primary focus of the case study, we acknowledge that the components of the incontinence management package are complementary and are not operating in a silo, recognising that the contribution towards change for people living with incontinence comes from the entire package and not just the training.

<sup>&</sup>lt;sup>1</sup>Gjerde, J.L., Rortveit, G., Muleta, M. and Blystad, A. (2013) Silently waiting to heal: Experiences among women living with urinary incontinence in northwest Ethiopia. International Urogynecological Journal.

<sup>&</sup>lt;sup>2</sup>Rosato-Scott, C., Adjorlolo, S., Farrington, M. & Barrington, D. J., (2024). 'Do not forget us': the shared experiences and needs of people living with incontinence in humanitarian contexts. Journal of Water, Sanitation and Hygiene for Development, 1 March.14(3).

<sup>&</sup>lt;sup>3</sup>Tanzania, Venezuela, Ethiopia, Syria, Chad and DRC.

### Summary of Methodology

The case study explored five primary research questions:

- 1. Which humanitarian problem(s) does the innovation address?
- 2. How does the innovation aim to address the problem, and how does it compare to existing solutions (if any)?
- 3. How effective has the innovation been in reaching its intended objectives?
- 4. What impact has the innovation achieved so far and what is the potential for the innovation to achieve further impact in the future and effectively address the problem at scale?
- 5. What key learning has emerged from the innovation?

The case study captures reflections from 17 interviews with the project members, partners, trained practitioners in Malawi and external observers. We also draw on experiences from facilitators and practitioners trained in Ukraine and Lebanon and research conducted by the project team since 2019. However, this case study refers to findings from Malawi, unless otherwise clearly stated. More details on the methodology and informants can be found in Annex 1.



### THE HUMANITARIAN PROBLEM



Incontinence is recognised as a global health, protection and WASH issue, however, there is limited experience and data available to understand its scope and implications especially in lower and middle-income countries.<sup>4</sup> While it can impact anyone, certain groups are at higher risk, including older adults and people who have been through stressful events like conflicts or natural disasters.<sup>5</sup> Despite its prevalence, incontinence remains a highly sensitive and often taboo topic making it difficult for those affected to seek help.<sup>6</sup> This creates challenges in both daily life and when accessing humanitarian aid.

In humanitarian situations, incontinence is often overlooked as humanitarian actors prioritise basic needs like food and shelter. Yet, without access to enough water and soap, managing incontinence becomes even harder. According to the Sphere Association, people with incontinence need up to five times more water and soap than those without this condition, but such resources are often scarce in crisis situations.<sup>7</sup>

Incontinence can lead to severe social, emotional, and physical challenges, however, organisations report that it is hard to identify people living with the condition or their caregivers, due to the difficulties talking about it. This often results in their exclusion in the design and decisions behind WASH facilities, for instance, toilets being too far away from households or not adapted for older people with incontinence to use.<sup>8</sup> These challenges are exacerbated by the limited awareness of the issue among humanitarian WASH, protection and health practitioners and decision makers.<sup>9</sup>

"It affects their dignity and, in general, the dynamics between households, between carer and person with incontinence, which can lead to increased abuse or negative coping mechanisms. In the context of humanitarian situations, it also limits accessing humanitarian aid. Incontinence is de-prioritised, of course, they prioritise food and immediate basic needs. So, it has multiple impacts on somebody's life, both to the person who suffers from it and also their surrounding family and caregiver."

WASH Practitioner

There are various open-source guidelines and resources on incontinence management (examples in Annex 3), however, they are mostly targeted to the WASH and health sectors and often within the global north. Information on managing incontinence in the humanitarian sector and within lower-income countries is still limited. Additionally, many existing resources regard incontinence as a women's reproductive health or disability issue, leaving significant gaps for other groups, including older people.

The humanitarian practitioners training complements these existing resources by targeting medical and non-medical staff. It is open to and usable by practitioners across the WASH, health and protection sectors within the humanitarian context. It improves knowledge and awareness of incontinence management and how to provide dignified support.

"The training is about providing information on different types of incontinence, the severity, the scale of incontinence, but also, what can WASH actors do when they are responding and how they could support people suffering from incontinence? So really trying to empower the team on the ground to feel like incontinence is not just a medical condition, it's something that we could understand, we could support as a WASH or health actor. So that's why the training pack has been developed."

Project Team Member

<sup>&</sup>lt;sup>4</sup>Rosato-Scott, C. et al., (2020). Incontinence: We Need to Talk About Leaks. *Frontiers of Sanitation*. October, Issue 16, p. 4. <sup>5</sup>Ihid

<sup>&</sup>lt;sup>6</sup>Gjerde, J.L., Rortveit, G., Muleta, M. and Blystad, A. (2013) Silently waiting to heal: Experiences among women living with urinary incontinence in northwest Ethiopia. International Urogynecological Journal.

<sup>&</sup>lt;sup>7</sup>Rosato-Scott, C. et al., (2020). Incontinence: We Need to Talk About Leaks. *Frontiers of Sanitation.*, October, Issue 16, p. 4.

<sup>8</sup>Oxfam, HelpAge, MANEPO, (2020). Understanding the Barriers to Inclusion of Older People with Incontinence in Humanitarian WASH Programming. s.l.:s.n.

<sup>&</sup>lt;sup>9</sup>Oxfam, HelpAge, MANEPO, (2020). Understanding the Barriers to Inclusion of Older People with Incontinence in Humanitarian WASH Programming. s.l.:s.n.

### THE INNOVATION



The humanitarian practitioner training on incontinence management aims to raise awareness about incontinence and provide staff with the knowledge and skills to better support those affected. It is designed for workers in the WASH, health, and protection sectors, focusing on the types of incontinence, its impact, and practical strategies for managing it in humanitarian contexts. A key emphasis is on involving people with incontinence in decisions about their care, and the products and facilities they need to access.

This training seeks to break down the stigma surrounding incontinence, showing that it is not just a medical condition, but a challenge that can be addressed through practical support. This approach aims to empower humanitarian practitioners to provide dignified care and improve the quality of life for people living with incontinence in difficult situations. Furthermore, the training encourages participants to consider the referral pathways for people who disclose their condition, so those who feel comfortable can seek additional treatment and support. The training fills a significant gap in humanitarian programming by helping workers understand incontinence better and promoting inclusive care that upholds the dignity of affected individuals.

"The training encourages WASH practitioners to ensure that their programming does not leave out interventions on incontinence, quite often humanitarian WASH programming has not included incontinence related interventions. So it's technically building the capacity of humanitarian WASH actors to ensure that their programming should be inclusive of incontinence related interventions... The training is looking at how to manage incontinence in different settings, even at home. So that they can consider tailor-made incontinence management using the local resources."

- Project Team Member

The training addresses the humanitarian problem by:

- Sharing detailed information on incontinence, including its causes and effects on different groups, through case studies and practical examples.
- Providing a non-clinical approach to understanding incontinence, challenging myths like the assumption that it only affects older people or women who have given birth.
- Presenting practical support strategies for encouraging individuals to disclose their condition, managing hygiene, and creating assistive products from locally available materials.
- Creating a safe learning environment where practitioners can ask questions and learn how to discuss incontinence sensitively and respectfully, contributing to reducing stigmatisation.
- Encouraging practitioners to have policy discussions on incontinence management within the WASH, health, and protection sectors in humanitarian settings.

### The Innovation Journey

Elrha initially funded three studies (2019–2021) to explore the needs of people with incontinence in humanitarian settings aimed at addressing knowledge gaps related to incontinence among children, women with fistula and older people.

This was followed by a short-term project in 2023 by Oxfam, Research and Grant Institute of Ghana (ReGIG), and the University of Western Australia to develop a training guide on incontinence management for WASH practitioners but was also relevant to protection and health practitioners. This guide built on the lessons learned across the three studies and aimed to enhance the confidence, knowledge, and practical understanding of incontinence management within WASH international non-governmental organisations (NGOs), national NGOs, and United Nations (UN) agencies. It was piloted with Oxfam, MANEPO and HelpAge staff and updated based on the feedback received.

The current Elrha funding (2023–2024) aims to develop a comprehensive incontinence management package to give older people and their caregivers more control over the dignified management of their incontinence during



humanitarian crises and be better supported by WASH and other actors. This includes the roll out of the humanitarian practitioner training.

### Elrha Contribution

Elrha has supported the development and dissemination through three separate grants, totalling £196,029.

Grant 1: Improving the lives of older people - Understanding barriers to inclusion of older people with incontinence in humanitarian WASH programming

Budget: £89,326

Funding awarded by Elrha: £61,498; Funding awarded by other sources: £27,828

**Duration:** December 2019 – December 2021 (24 months)

**Grantees:** Three separate cohorts:

- 1. University of Leeds and the University of Western Australia focused on incontinence in children in Bangladesh and Uganda.
- 2. ReGIG studied women with obstetric fistula-induced incontinence in Ghana.
- 3. Oxfam and HelpAge International incontinence in older people in Malawi and Ethiopia.

#### Grant 2: Creation of a package of incontinence training materials for WASH practitioners

Budget: £28,780 (awarded from Elrha).

Duration: March 2023 – June 2023 (3 months).

Grantee: Oxfam, Partners: Research and Grant Institute of Ghana, University of Western Australia/University

of Leeds

This follow-up funding set out to develop a training package on incontinence management that provides practical guidance to WASH practitioners.

### Grant 3: Inclusion of people with disabilities and older people from research to action: Learning from older people with incontinence across 11 humanitarian contexts

Budget: £217,127. £105,751 (awarded by Elrha). £111,376 (funding from Oxfam).

**Duration:** April 2023 – November 2024 (this project is currently ongoing) (20 months)

**Grantee:** Oxfam, **Partners:** HelpAge International, MANEPO

The grant aims to address gaps in knowledge and practice around incontinence in the humanitarian sector through four areas:

- The development of a home-based care training package
- Feedback from older people on appropriate items for managing incontinence in their context
- Incontinence questions to be routinely incorporated into surveys and needs assessments
- Roll out of the humanitarian practitioner training on incontinence management

### Costs

**Training package development costs:** The total cost of developing the training documents was £23,980. This included consultant fees, staff time, the design of the training pack, and translations into French and Spanish.

**Non-financial support** for the development and implementation of the training was received from the project partners, Oxfam, ReGIG, University of Western Australia, MANEPO and HelpAge who offered time beyond budgeted fees.

**Implementation costs:** The total direct cost for rolling out the training across 11 countries is estimated to be £59,400.10 (27% of the total £217,127 budget). The average cost to roll-out the training to one country is approximately £4,200, excluding travel costs for facilitators. Each training is expected to include 20 participants.

The benefit of Elrha's investment in the incontinence management package is not yet realised as the project is still ongoing. However, feedback from Malawi, Ukraine and Lebanon on the training have been positive, with practitioners becoming more aware of incontinence and how to manage incontinence. It is anticipated, after rolling out the training across 11 countries and any updates made, the training guide will be open-source and available to all. Consequently, there are limited scaling costs for the future. The project team is also building connections and partnerships to promote and enable further use of the training and therefore it is anticipated that these upfront investments will mean the work to support people living with incontinence will continue after the project finishes.



### **EFFECTIVENESS**



The training on incontinence management aimed to increase the confidence, knowledge, and practical skills of humanitarian workers in WASH and related sectors and encourage all humanitarian actors to recognise the role they have in addressing incontinence. The main learning objectives were to help practitioners understand incontinence, assess the needs of those affected and their caregivers and address the stigma associated with incontinence in WASH programming.<sup>10</sup>

In Malawi, 16 practitioners completed the training. Participants interviewed (n=3) reported a significant improvement in their understanding of the causes, types, and prevalence of incontinence. One health worker explained that the training broadened their knowledge beyond birth-related fistulas to encompass the social and psychological impacts of incontinence on various groups. Caregivers (n=2) gained practical skills for supporting individuals with incontinence, such as offering emotional support and providing appropriate materials.

Participants appreciated the training's use of case studies, data and conversational approach, which helped highlight the importance of tackling the stigma surrounding incontinence. One participant noted that it was the first time they had received training on the topic in over a decade of working in the WASH sector. The training empowered participants to identify ways to support people with incontinence and integrate these insights into their work. Group exercises further helped improve communication skills, allowing them to better empathise with those affected by incontinence. They continue to share their learning with their peers in and out of their organisations.

"By showing them (participants) the results from the first phase (research conducted in 2019), that brought up a lot of discussion, and people started to understand this is a big issue. People were not paying much attention to it since they believed it doesn't have a cure, but now we have started realising how important it is to talk about this issue and find different ways of how we can try to manage it."

- Training Facilitator

### **Enablers of Success**

**Complementary partnership**: The combined expertise of various organisations and consultants played a critical role in designing, developing, and rolling out the training. Their experience in different sectors ensured that the training was well-rounded and relevant to different sectors.

**Buy-in from key stakeholders:** Support from key organisations and WASH cluster coordinators was essential. For instance, the health ministry in Malawi helped mobilise participants and foster policy interest in incontinence management.

**Practitioner commitment**: As a first-of-its-kind training on a taboo topic, participants were highly engaged and excited, which enhanced learning and interaction. Participants showed strong interest in understanding incontinence and supporting affected individuals, boosting the programme's effectiveness.

**MANEPO's network and experience:** Their strong connections and experience in older persons care allowed them to mobilise diverse participants and tailor the training to address the specific needs of older people.

"Now, whenever I'm conducting activities (with older people) for different projects outside of incontinence management, I always make sure to set aside time to talk to them about incontinence and how they can manage it, as well as how to make things to help them manage it. For them to understand that they can manage it locally, using locally produced resources. For example, they can make commodes out of the chairs they already have. And trying to make them understand that this is a health issue, that they should not be embarrassed about it, and that they should open up to their relatives and tell them they need help managing it so that they can get the assistance they require."

- Training Facilitator

<sup>&</sup>lt;sup>10</sup> In-person training guide.



Furthermore, MANEPO's experience allows them to assist other trained practitioners who wish to help, for example, through providing clarifications and sharing information on assistive products and local suppliers.

### Challenges

Limited training time: Both participants and staff felt that the training was too short. They suggested extending it to 2–3 days to allow more time for reflection, discussion, and practical application. The project also faced challenges delivering the training across 11 countries within a tight schedule.

**Language barriers:** There is no direct translation for "incontinence" in many local languages in Malawi. This made it difficult to talk about the issue accurately without sounding too medical or misrepresenting it.

**Cultural beliefs:** Strong beliefs around incontinence, such as attributing it to witchcraft<sup>11</sup> or relying on ineffective herbal remedies, made it hard for practitioners to apply the training. Behavioural change is essential, but some people resist medical explanations. This presents the challenge of how practitioners may engage with cultural beliefs and adapt training to acknowledge and harness these to improve the impact of the training.

"Where persons with incontinence ascribe it to spiritual forces and look for spiritual means to address it, then it doesn't matter how much training and education you give them. Once they focus on that, it becomes so difficult to actually transfer the training. People need to be willing to accept what you have and what you can give them."

- Project Partner

### **Ethical Considerations**

The incontinence training is designed with strong ethical, equity, and inclusion principles. The project team's main focus was to ensure that no activities increase embarrassment, stigma, or stress for those living with incontinence. To address this, the training includes a dedicated session on minimising harm when discussing the condition. It also specifically addresses the different ways incontinence affects various groups, including children, women, older adults, and people with disabilities, equipping practitioners with the skills to provide inclusive, effective support.

One concern raised by interviewees was the risk of increased stigma if individuals were encouraged to disclose their condition without first sensitising the community. The training covers how to handle stigma and encourages practitioners not to diagnose incontinence unless they are medically trained, as there is a risk that some may overstep their role after gaining knowledge.

Furthermore, the lack of clear referral pathways makes it difficult to provide the necessary support to people living with incontinence. According to Rosato-Scott et al, (2024), practitioners should establish referral pathways and services before discussing incontinence, as these may result in people living with incontinence requiring support beyond what can be provided, such as medical or protection support. The training covers identifying referral pathways, however having effective referral pathways in place can be challenging in humanitarian contexts where access to services is limited.

<sup>&</sup>lt;sup>11</sup>Oxfam, HelpAge, MANEPO, (2020). Understanding the Barriers to Inclusion of Older People with Incontinence in Humanitarian WASH Programming. s.l.:s.n.

### **IMPACT**



The current and potential impact of the humanitarian practitioner training, while still emerging, shows promising signs of positive change for incontinence management:

Integration into existing programmes. Facilitators have started incorporating discussions on incontinence into activities with older people, teaching them how to manage their condition with local resources. By encouraging open communication about their needs, this approach not only addresses practical issues but also restores dignity by acknowledging and validating their struggles, which were often hidden due to stigma. This will likely lead to improved emotional well-being for individuals living with incontinence, who feel relieved that the issue is being acknowledged.

"I think most of them (elderly people) feel happy that someone is acknowledging it (incontinence) and talking about it with them, since it's something that most of them are depressed and stressed about."

- Training Facilitator

**Improved caregiving.** Participants have reported providing more compassionate care to family members with incontinence, focusing on maintaining hygiene, offering emotional support and involving the household in providing assistance. This is important as previous research in Malawi found that most people living with incontinence who were interviewed received no support.<sup>12</sup>

**Increased awareness and support-seeking.** There is anecdotal evidence that people with incontinence are more aware of how to seek help as a result of the training, having previously struggled to find appropriate services. The training has helped practitioners guide individuals on where to seek care and support.

**Organisational commitment.** MANEPO has committed to mainstreaming incontinence management into its wider programming, ensuring continued support for older people living with incontinence. This includes plans to raise awareness and push for policy changes in humanitarian platforms and supporting the Malawi Ministry of Health to strengthen incontinence management in their healthcare policies.

**Greater practitioner confidence and knowledge.** The training has equipped practitioners with the knowledge to treat incontinence as a holistic issue (medical, social, and psychological). By fostering open discussions and promoting inclusive, respectful language, practitioners can help reduce the stigma that undermines the dignity of those living with incontinence, ensuring they receive empathetic and appropriate care. Practitioners, especially those in the health sector felt more confident and comfortable talking about incontinence more openly.

"Two years ago, open discussions on incontinence were not so seen in daily practice."

- Trained Practitioner - Medical

The training also highlighted the importance of inclusive, non-stigmatising language, with efforts underway to reframe how incontinence is addressed in various humanitarian settings.

"My late grandmother had this issue, but I didn't know that there is literally a term and that it's a health issue called incontinence. I just thought it was just a normal thing that happens to elderly people when they're growing older... After the training I started talking to my friends, asking them if they know what incontinence is? Everyone I was asking did not know what incontinence was. When I explained in our local language, what it really is, some said they had read about it and knew someone who had incontinence."

- Trained Participant.

<sup>&</sup>lt;sup>12</sup>Oxfam, HelpAge, MANEPO, SJOG, 2021. Improving the lives of older people Understanding barriers to inclusion of older people with incontinence in humanitarian WASH programming. s.l.:s.n.



There is a strong sense that the training empowers humanitarian workers to support people living with incontinence, ensuring that their dignity is maintained, reducing stigma and isolation. Working towards enabling people to receive appropriate care and support in challenging environments.

The main barriers to systemic change identified include:

**Prioritising incontinence management** requires the commitment of organisational decision-makers, but conflicting agendas often hinder this. As one potential adopter noted, convincing leaders of the widespread impact of incontinence and the need for empathy, funding, and time to address it is a major challenge. Without this buy-in, integrating incontinence management into routine practices remains difficult. This is coupled with the resource limitations to integrate incontinence management into existing programmes, conduct outreach, or offer refresher training. This also affects households, where caregivers struggle to afford essentials like soap, protective bedding, and assistive products, while balancing caregiving with earning an income.

"You can have staff, but essentially if you want to support people living with incontinence, they either need an assistive product, or an adaptation in the house, or they need some constant care and support. What's the reality of moving this forward?"

- Project team member

**Limited incontinence referral pathways.** Interviewees across all categories stated that they did not always know where to refer people living with incontinence for additional WASH, health, and protection support. For example, when people needed soap, they did not always know how to help them get it. This was also identified as a barrier in previous research in Malawi and Ethiopia.<sup>13</sup>

As stated by a health worker trained in Malawi, "In the district, there are no referral pathways for incontinence. However, this project serves as a wake-up call to get started."

**Difficulty moving from learning to changing practice.** Trained practitioners have increased their awareness of incontinence management. However, they do not always have the time or resources to implement that learning, prioritise changing practices based on the training and or decision-making power.

Attitudes and beliefs towards incontinence: The project team and partners saw barriers around how practitioners maintain fidelity of the training. While the training aims at building the capacity of practitioners to be able to incorporate lessons learnt into their practice, it was recognised that how this is done will vary from one practitioner to another, with the risk of some not doing it too well.

"In reality, some may transfer the skills and knowledge, some may not. And even for those who transfer, there could be variations and different levels of application. Where some will apply the knowledge perfectly, for some, it will be based on personal expectations, prejudices, stereotypes and biases."

-Project Partner

Additionally, personal attitudes and beliefs among practitioners and people living with incontinence could hinder them from effectively engaging with the topic without being influenced by existing stereotypes, myths and beliefs. As perceived by a project partner, "the acceptance and openness of the people to talk about it and to start dealing with it openly, is like changing the mentality and changing the stigma around the topic."

<sup>&</sup>lt;sup>13</sup> Oxfam, HelpAge, MANEPO, SJOG, 2021. Improving the lives of older people Understanding barriers to inclusion of older people with incontinence in humanitarian WASH programming. s.l.:s.n.

### **CONSIDERATIONS FOR SCALE**



Overall, at least 137 practitioners have been trained from five countries (details on participants trained in each country are provided in Annex 3). The training is projected to reach over 200 practitioners in 11 contexts by the end of the project, increasing their knowledge of incontinence and issues affecting older people.

For broader scalability, feedback suggests that the introduction of a short, self-guided course on incontinence management and a Training of Trainers model would allow facilitators to adapt the content more easily while maintaining quality, reducing the dependence on Oxfam, HelpAge, and MANEPO for delivery. The flexibility of these formats would make the training more accessible and sustainable.

A crucial factor for scaling is the willingness of donors and humanitarian organisations to incorporate incontinence management into existing WASH, health, and protection programmes. Additionally, the WASH sector must play an active role by mobilising practitioners, prioritising incontinence management in decision-making and driving policy discussions. Continued commitment from trained practitioners is also essential. Their influence, especially those in leadership roles, can help embed incontinence management into broader health and disaster risk management interventions, sourcing materials and support for people living with incontinence during crises.

Lastly, government engagement is vital for scaling efforts. The Ministry of Health in Malawi has shown interest in improving incontinence management, creating a supportive environment for health workers to apply their training. Similar government commitment in other countries will be crucial for incorporating incontinence management into national policies and ensuring long-term impact.

### Plans for Scale

The project team will continue rolling out the training across all planned contexts. Each training will include an action planning session to support the incorporation of learning into programme activities. The project team will provide periodic follow-up to assess progress and support participants in delivering their action points.

Once the rollout of the training is finished, by 30<sup>th</sup> November 2024, Oxfam and HelpAge will publish the training manual on their websites, open-source. HelpAge will facilitate webinars on incontinence management with their network. They also plan to strengthen their network of incontinence management champions through existing structures in Malawi, such as the Red Cross, World Vision and the government.

Oxfam and Norwegian Church Aid (NCA) are currently discussing a potential collaboration to align their respective guides, which may enhance long-term scalability. Since the training and the NCA toolkit are complementary, there is an opportunity to refer participants who want more detailed information from the training to the toolkit (and vice versa).

### WHAT HAVE WE LEARNT?



Implementation and scaling of the humanitarian practitioner training for incontinence management has highlighted five key learnings:

#### Advancing Incontinence Care: Toward empathetic and holistic support

This innovative training is a critical step in addressing the often-overlooked issue of incontinence in humanitarian contexts. By equipping practitioners with essential knowledge and practical skills through the training, they are enabled to provide more effective and empathetic support to individuals living with incontinence. Feedback from the training shows positive signs of helping to reduce the stigma surrounding the condition, fostering an environment where incontinence is discussed openly, and those affected can seek the care they need with dignity.

### Cultural and contextual adaptability are essential.

Successful innovation in humanitarian settings requires not only technical solutions but also deep understanding of local contexts and the emotional, psychological, and social dimensions of the problem. The project team and partners found that cultural and contextual factors strongly influence how the target audiences interact and apply the training. They also recognised the risks of people getting offended or embarrassed by certain topics.

Elrha's long-term funding for this topic has enabled the organisations involved to deeply understand the issue across different populations and contexts. This has been developed into an evidence-based training programme focusing on sensitive, inclusive, and dignified approaches to supporting people living with incontinence. By promoting the involvement of people with incontinence in decision-making about their care and focusing on culturally appropriate, locally available solutions, the training addresses significant gaps in current incontinence management.

#### The training promotes sensitivity in approaches to managing incontinence.

Incontinence has significant emotional, social, and psychological impacts on both individuals living with the condition and the practitioners who support them. The training emphasised the need for handling the topic with care, stressing confidentiality, appropriate language, and ensuring participants' consent. To enhance its reach and sustainability, developing a "Training of Trainers" package is recommended. This would allow the training to be further scaled, reduce dependence on the project team, and maintain the quality and consistency of the programme.

#### Government and organisational buy-in are critical.

Leadership and policy support, as demonstrated in Malawi, play a key role in driving change and providing long-term support for individuals living with incontinence. Securing commitment from both governments and organisations is essential for scaling and integrating incontinence management into broader health and humanitarian programmes, ensuring the sustainability of these efforts. Without this buy-in, progress will be limited, and practitioners may find it difficult to implement their learnings effectively.

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### In Conclusion

Early feedback suggests that the incontinence management training is contributing towards improving care and support for people living with incontinence in humanitarian settings. By equipping practitioners with essential skills and knowledge, it addresses both the practical and emotional needs of affected individuals, while also working to reduce the stigma associated with the condition. The training as part of the wider incontinence management package is well-positioned to create positive change in the way incontinence is understood and managed in humanitarian contexts, ultimately improving the dignity and quality of life for those affected.



### **ANNEXES**



### Annex 1: Methodology

Case study development entailed the following six steps:

#### 1. Inception

We held an inception meeting with Elrha to finalise the research questions, agree on the methodology and develop the data collection tools. We also conducted a document review of both academic and grey literature. We used a structured template to synthesise the information against each research question to enable further analysis and triangulation of different data sources. The document review was used to analyse the existing evidence available, which was later triangulated with the primary data collected.

#### 2. Exploratory sessions

We conducted an introductory session with the project team, Oxfam, HelpAge and MANEPO, to understand the innovation better and its current status. We also facilitated a session with the team to understand the changes they envisioned the incontinence management package making and the assumptions on how this change would happen.

#### 3. Key informant interviews

We conducted 17 online interviews, guided by a semi-structured template with open-ended questions that lasted 45-60 minutes. The project team identified the interviewees. If they were unavailable or unresponsive, we substituted them with another informant(s) on the list. We conducted 17 interviews as indicated in the table on page 21.

#### 4. Analysis

We used thematic analysis, coding the primary data against the research questions, changing areas and key assumptions to identify the key trends to inform the findings. Secondary data, including a pre/post training survey in Malawi, which received 16 responses, supported triangulation and contextualisation.

#### 5. Validation meeting

We presented emerging findings from the data collection to the project team and Elrha for reflection, validation and feedback.

#### 6. Case study drafting

We then developed the case study, which underwent two rounds of feedback from Elrha, the project team and other key stakeholders. A long draft of findings was heavily summarised to produce the final case study report.

Table 1: Case study participants breakdown

Category	Organisation	No. of representatives
Project team: Involved in the design	Oxfam	2

and rollout of the training and project management.	MANEPO	3
Project partners: Organisations and consultants involved in the design of the training and research and supported the roll-out of the training.	HelpAge	2
	University of Western Australia	1
	ReGIG	1
	Lebanon WaSH Sector	2
	Independent Consultant	1
Humanitarian practitioners trained in Malawi	Blantyre District Health Office	1
	Chikwawa District Health Office	1
	Evidence Action	1
Potential adopters: People/organisations interested in incorporating the training into their work.	Norwegian Church Aid	1
External observer: People/organisations with no direct project involvement but possess a strong understanding of the sector and contexts.	Institute of Development Studies	1

### **Limitations**

There were three main limitations as follows:

- The roll out of the humanitarian practitioner's training on incontinence management was still ongoing
  and had been conducted in four countries at the time of data collection which made it difficult to draw
  firm conclusions on impact, effectiveness and potential to scale. It also presented challenges in collecting
  data on the project's costs for development and implementation.
- It was difficult to identify potential adopters as the training was in the process of being rolled out.
- We interviewed a small number of practitioners trained in Malawi which limited how much perspective we could get on the training and initial changes it has brought about.

## Annex 2: Examples of Guidelines and Resources on Incontinence Management

- We need to talk about leaks: Practical guidance on identifying, engaging with and supporting people living
  with incontinence by the University of Western Australia and London School of Hygiene & Tropical
  Medicine
- The World Health Organization's (WHO's) Global Report on Assistive Technology and <u>Training in Assistive Products</u>: This is modular training and guidance on using assistive products.
- NCA's <u>Mapping of Support for People Living with Incontinence in Humanitarian Contexts</u> and resulting training, which includes a detailed toolkit, guidelines for incontinence management and Training of Trainers for staff.
- Mapping and Evidence Synthesis for Assistive Technologies to Support Adults Living at Home with Longterm Incontinence or Toilet-use Problems; research by the University of Southampton.
- Research, toolkits, and guidance documents shared in the informal community of practice.

### Annex 3: Number of People Trained as of September 2024

County	Number of Participants
Malawi	16
Lebanon	28
Yemen Online	15
Yemen In Person	17
Ukraine	5
South Sudan	44
Oxfam/HelpAge staff	12
Total	137



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October 2024

Commissioned by Elrha's Humanitarian Innovation Fund

### **ABOUT ELRHA**

Elrha is a global organisation that finds solutions to complex humanitarian problems through research and innovation. The innovations funded through our Humanitarian Innovation Fund (HIF) identify, nurture and share more effective and scalable solutions to some of humanity's most difficult challenges. The HIF is funded by the UK Foreign Commonwealth and Development Office (FCDO) and Norway.



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