



## Children and their caregivers' experiences with incontinence

*A research and practice partnership to understand and dismantle the barriers to inclusion and well-being that children (aged five to 11), and others living with incontinence, face in humanitarian contexts*

**Scope:** The research will be undertaken in Adjumani District, Uganda; and Cox's Bazar, Bangladesh.

**Time-frame:** 1<sup>st</sup> January 2020 to 31<sup>st</sup> August 2021 (project activities to be completed by 30<sup>th</sup> June 2021)

**Funding Amount:** £51 943

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**Overall objective of the research:** Understand the barriers to inclusion and well-being that those living with incontinence, particularly children aged five to 11 and their caregivers, face in humanitarian contexts, so that more holistic, effective and inclusive WASH and protection programming can be developed.

### Specific objectives:

1. Develop and assess a collaborative story book methodology to engage children (aged five to 11) in humanitarian contexts in discussions of sensitive topics;
  - a. Co-develop methodology with local staff, child protection specialists and facilitators of child-friendly spaces;
  - b. Assess the usefulness and appropriateness of the tool for prompting discussions around incontinence, and sensitive issues more broadly;
2. Collect data on attitudes towards and experiences of incontinence from children (aged five to 11), their caregivers and enabling actors through interviews, focus groups and collaborative story book methodology in a) Adjumani (Uganda) and b) Cox's Bazar (Bangladesh);
  - a. Determine the issues of incontinence related to WASH, inclusion and protection;
  - b. Determine what facilities, resources and services are currently provided for those with incontinence, particularly children;
  - c. Understand the experiences of and attitudes towards incontinence of children, their caregivers, and the wider humanitarian community;
  - d. Understand how emergency WASH programming can be improved for those with incontinence, particularly children, and their caregivers.
  - e. Understand how emergency protection programming can be improved for those with incontinence, particularly children, and their caregivers.
3. Prepare and disseminate results, recommendations and methodologies that can be used in developing more holistic, effective and inclusive humanitarian programming.
  - a. Co-create dissemination packages with local staff, child protection specialists and facilitators of child-friendly spaces;
  - b. Co-create inclusive dissemination strategy with local staff, child protection specialists and facilitators of child-friendly spaces.

**Rationale for the research:** Incontinence is often considered a condition related to age or disability, yet best estimates indicate that a) 1 in 12 adults will leak faeces before they are 70; b) almost half of all women will leak urine; c) almost 1 in 10 seven year old children will leak urine during the day; and d) up to 1 in 5 children aged five will wet the bed. Prevalence rates may be higher in emergency contexts as:

- Exposure to stress can contribute to bedwetting in children, and refugee status has been found to be a risk factor for the occurrence of night-time leakage.
- Violence (from partners, parents, teachers, communities, other children) can lead to incontinence in females and males of all ages.
- Childbirth can result in urinary and fecal incontinence, particularly through obstetric fistula, caused by prolonged obstructed childbirth. The risk of fistulas is higher in humanitarian contexts where there is insufficient obstetric care; and mothers may be younger (e.g., child brides), have experienced female genital mutilation, or are observing Purdah (and are thus limited in their access to toilets and healthcare).

Leakage can also occur when a person has full control of their bladder but doesn't want to, or isn't able to, use the sanitation facilities available, for example, at night in a refugee camp a child may urinate in their bed instead of using a public latrine (this is known as social incontinence).

If people with incontinence face barriers to accessing facilities and services to manage the condition, their physical health can suffer (rashes, infections, pressure sores, dehydration). They also often miss out on educational and livelihood opportunities, and have increased protection risks due to stigma. If the global community is to achieve the Sustainable Development Goals, particularly those relating to universal sanitation (Goal 6) and well-being (Goal 3), there is a need to better understand the occurrence of incontinence in humanitarian settings, and how multilateral and non-governmental organisations can best support those with the condition.

**Methodology:** Qualitative participatory data collection tools will be co-created by the research team, local staff, child protection specialists and facilitators of child-friendly spaces. Participants will be children aged five to 11, caregivers and local enabling actors (e.g., humanitarian specialists, teachers, health workers). Given the sensitive nature of the topic, data collection will focus more generally on understanding toileting behaviours and participant awareness / understanding of / attitudes towards incontinence. This may not be based on their own experience of the condition and it is hoped that this approach will help unpick the stigma associated with incontinence and provide a deeper understanding of how the condition can be best managed in an emergency context.

**Outputs:** Outputs will be determined and co-created by the research team, local staff, child protection specialists and facilitators of child-friendly spaces, and will include sharing of aspects of the dissemination package with research participants.

## The Team

**University of Leeds** – Lead organisation, Dr Dani Barrington, Professor Barbara Evans & Claire Rosato-Scott

**The University of York** – Co-investigator, Dr Jo Rose

**Plan International / UNICEF / World Vision** – Implementing partners, led by Huda Ghalegolabi (Plan International) and Preetha Prabhakaran (UNICEF)

**Advisory Committee** – Humanitarian specialists (Dr Sarah House, Eva Niederberger), incontinence specialists (Professor Linda McGowan, Dr Maggie Wu, Dr Pete Culmer, Dr Amy Hunter, Dr Lena Jaspersen, Dr Bethan Davies), specialists in conducting research with children (Dr Gill Main, Dr Hayley Davies)

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