Emergency sanitation for children with urinary incontinence

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for the degree of Doctor of Philosophy

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Intellectual Property and Publication Statements

- This PhD has been submitted as a PhD by Publication and the research has been reported as journal articles throughout the candidature. To the best of the PhD Candidate's knowledge, the subject matter of this PhD (emergency sanitation for children with urinary incontinence) has long been neglected across those sectors best placed to support children in an emergency context who are experiencing urinary incontinence, and their caregivers. These sectors include health (including nutrition and occupational therapists); protection; gender-based violence; disability; children; gender; livelihoods; and water, sanitation and hygiene (WASH) (Rosato-Scott et al., 2020). Dissemination of research methods used, research findings and lessons learned as soon as possible was therefore felt to be most appropriate as a means to encourage all sectors to start thinking about how to provide appropriate and effective support to children with urinary incontinence, and their caregivers (Rosato-Scott et al., 2020).

- This PhD has been constructed to address the primary research question (PRQ) 'how is urinary incontinence in children aged five to 11 best understood and managed during an emergency?'; and the three secondary research questions (SRQ):

    - SRQ1. What is best practice guidance for the provision of emergency WASH facilities, resources and services for children aged five to 11, including those with urinary incontinence; and what is currently provided?:

    - SRQ2. How can the prevalence of urinary incontinence in children aged five to 11 be determined in an emergency context?; and

    - SRQ3. How can children participate in the design of emergency sanitation programmes to improve the provision of emergency sanitation for children aged five to 11, including those with urinary incontinence?

- This PhD therefore incorporates a literature review and four manuscripts, followed by a final discussion and conclusion:

    1. Introduction

    2. Literature Review

- Part 1: The provision of emergency sanitation for children aged five to 11 with urinary incontinence (Addressing SRQ1; Associated with Manuscript 1)

- Part 2: The prevalence of urinary incontinence in displaced children aged five to 11 (Addressing SRQ2; Associated with Manuscript 2)

- Part 3: Understanding the impact of urinary incontinence on displaced children aged five to 11 (Addressing SRQ3; Associated with Manuscripts 3 and 4)

3. Manuscripts

    - Manuscript 1 (Published): CHILD-SAN: a new disability-inclusive framework for emergency sanitation for children aged five to 11, based on a systematic review of existing guidance (Addressing SRQ1)

    - Manuscript 2 (Published): Urinary incontinence in children aged 5 to 12 in an emergency setting: lessons learned in Ethiopia (Addressing SRQ2)

    - Manuscript 3 (Draft): Engaging with crisis-affected populations: An assessment of the User-Centred Community Engagement methodology as used in Tukaley, Ethiopia (Addressing SRQ3)

    - Manuscript 4 (Submitted): Understanding children's experiences of self-wetting in humanitarian contexts: An evaluation of the Story Book methodology (Addressing SRQ3)

4. Discussion

5. Conclusion

- The candidate confirms that the work submitted is her own, except where work which has formed part of jointly authored publications has been included. The contribution of the candidate and the other authors to this work has been explicitly indicated below:

a) Manuscript 1 (Published): Rosato-Scott, C.; Evans, B.E. and Barrington, D.J. 2021. CHILD-SAN: a new disability-inclusive framework for emergency sanitation for children aged five to 11, based on a systematic review of existing guidance. Journal of International Humanitarian Action. **6**(1)

The candidate initiated the report; conducted the systematic review and analysis; wrote the first draft of the manuscript; updated the manuscript for review comments; and read and approved the final manuscript. All other authors provided review comments; and read and approved the final manuscript. Dani Barrington also provided guidance on the overall study.

b) Manuscript 2 (Published): Rosato-Scott, C.; Evans, B.E.; Varampath, V.; Fehnert, B. and Barrington, D.J. 2021. Urinary incontinence in children aged 5 to 12 in an emergency setting: lessons learned in Ethiopia. *Waterlines*. **40**(3), pp.179-191

The candidate initiated the report; conducted the analysis; wrote the first draft of the manuscript; updated the manuscript for review comments; and read and approved the final manuscript. All other authors provided guidance on the overall study; provided review comments; and read and approved the final manuscript.

c) Manuscript 3 (Draft): Rosato-Scott, C. and Barrington, D.J. tbc. Engaging with crisis-affected populations: An assessment of the User-Centred Community Engagement methodology as used in Tukaley, Ethiopia. *Journal of Humanitarian Affairs.* **tbc**

The candidate initiated the report; conducted the analysis; and wrote the first draft of the manuscript. Dani Barrington provided guidance on the overall study and provided review comments.

d) Manuscript 4 (Submitted): Rosato-Scott, C.; Alam, M.; Evans, B.E.; Rose, J.; Wozei, E. and Barrington, D.J. tbc. Understanding children's experiences of self-wetting in humanitarian contexts: An evaluation of the Story Book methodology (Submitted). PLOS Global Public Health. **tbc**

The candidate initiated the report; conducted the analysis; wrote the first draft of the manuscript; updated the manuscript for review comments; and read and approved the final manuscript. All other authors provided guidance on the overall study; provided review comments; and read and approved the final manuscript.

- The candidate confirms that appropriate credit has been given within the thesis where reference has been made to the work of others.

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- The right of Claire Rosato-Scott to be identified as Author of this work has been asserted by Claire Rosato-Scott in accordance with the Copyright, Designs and Patents Act 1988.

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A huge thank you to my family, including of course my Mum, my partner and my children. This PhD would not have been possible without you all by my side every step of the way, and for that I will be forever grateful.

And finally, I would like to dedicate this PhD – and the decades of education on which it rests – to the memory of my Dad. I know he would have been very proud.

Abstract

Children aged between five and 11 years old sometimes wet themselves. This could be due to them having the medical condition of urinary incontinence (UI, defined as the involuntary leakage of urine), or due to them not wanting to use, or not being able to use, the toilet facilities available (known as social incontinence). Little is known about how children aged five to 11 experience self-wetting (due to either UI or social incontinence) when displaced from their homes, and how they can be better supported. As a result, humanitarian programmes in sectors including health, protection, and water, sanitation and hygiene may not meet the needs of children that wet themselves.

This research is the first known attempt to understand self-wetting in displaced children aged five to 11. It includes a systematic review of existing guidance for the provision of emergency sanitation for children aged five to 11, and the evaluation of two methodologies designed to address the operational and ethical challenges of conducting research with displaced children on personal and sensitive issues: the User-Centred Community Engagement (UCCE) methodology and the Story Book methodology.

Improving sanitation facilities will improve the quality of life of children with social incontinence and their caregivers. The CHILD-SAN framework will support the better provision of sanitation facilities for such children, and the framework can be enhanced by using the UCCE methodology. Improving the quality of life for children with UI and their caregivers – and also for children that may never be comfortable using public latrines and subsequently self-wet – is more challenging. Communication to normalise UI is a critical first step, and the inclusion of products in standardised hygiene kits to support the management of self-wetting would also help. The provision of such communications and incontinence kits can be improved by using the Story Book methodology.

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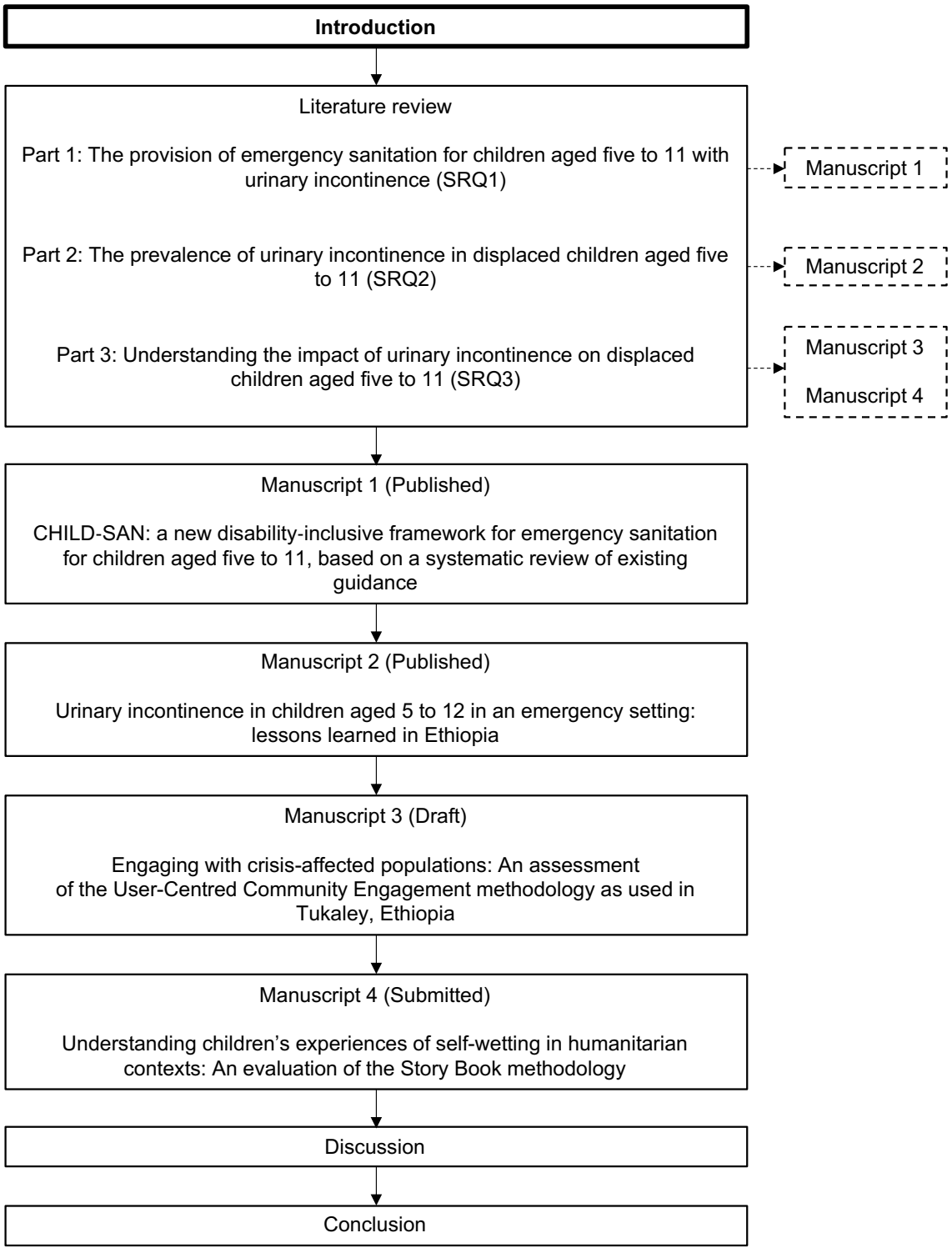
Abbreviations

AVP	Arginine vasopressin
BOO	Bladder outlet obstruction
CCCs	Core Commitments for Children in Humanitarian Action
CRC	Convention on the Rights of the Child
DUI	Daytime urinary incontinence
FGD	Focus group discussion
HIF	Humanitarian Innovation Fund
ICCS	International Children's Continence Society
IDS	Interactive Digital Survey
LUT	Lower urinary tract
MNE	Monosymptomatic enuresis
NFI	Non-food item
NMNE	Non-monosymptomatic enuresis
OAB	Overactive bladder
OCHA	United Nations Office for the Coordination of Humanitarian Affairs
PRQ	Primary research question
SDGs	Sustainable Development Goals
SRQ	Secondary research question
STCUK	Save the Children UK
UCCE	User-Centred Community Engagement
UI	Urinary incontinence
UN	United Nations
UNCRC	United Nations Convention on the Rights of the Child
UNICEF	United Nations Children's Fund
UNHCR	United Nations High Commissioner for Refugees
UTI	Urinary tract infection
WASH	Water, Sanitation and Hygiene
WHO	World Health Organisation

Emergency sanitation for children with urinary incontinence (Rosato-Scott)



Introduction

The United Nations Office for the Coordination of Humanitarian Affairs (OCHA) estimates that in 2022, 274 million people will need humanitarian assistance and protection (OCHA, 2021 p.9). This could include 55 million children aged between five and 11 years of age displaced from their homes[1], of which 5 million could be wetting themselves during the day and 11 million could be wetting themselves at night due to experiencing the medical condition of urinary incontinence (UI, the involuntary leakage of urine)[2]. There will also be children who do not want to, or are not able to, use the sanitation facilities available and choose instead to urinate elsewhere, including on themselves (known as social, or functional incontinence). When the cause of urination on the self is unknown (that is, it could be due to the child experiencing the medical condition of UI or due to social incontinence), the term 'self-wetting' can be used.

Research conducted in a non-emergency context has shown that children who wet themselves can experience skin rashes and/or urinary tract infections; be at risk of physical and/or verbal abuse by caregivers; and be isolated socially from both family and the wider community (Rosato-Scott et al., 2020). Such consequences can take an emotional toll on the child. Caregivers can struggle too, perhaps with not understanding the condition; or being able to find the resources (financial, time, energy) to wash clothes and bedding; or with negative emotions such as shame and embarrassment that may also lead to social isolation (Rosato-Scott et al., 2020). In a non-emergency context, non-medical measures to support families that experience self-wetting focus on the provision of knowledge about self-wetting (causation, treatment, management); products to contain the urine (pads, bed pans); and products to facilitate cleaning (mattress protectors, soap).

It is not known how prevalent self-wetting (due to either UI or social incontinence) is in displaced children aged five to 11, nor what the impact of self-wetting has on displaced

[1]In 2019, the United Nations High Commissioner on Refugees (UNHCR) estimated that of the persons of concern (being any person whom the UNHCR considers to be a refugee, a returnee, stateless, internally displaced or an asylum-seeker) it had demographic data on, 1 in 5 was aged between five and 11 years of age (UNHCR 2020).

[2]In a non-emergency context it can be assumed that 2.0-9.0% of children aged five to 11 wet themselves during the day, and 5.0-20.0% of the same age group wet themselves at night due to experiencing UI (Morison et al., 2004; Buckley and Lapitan, 2010; Abrams et al., 2017).

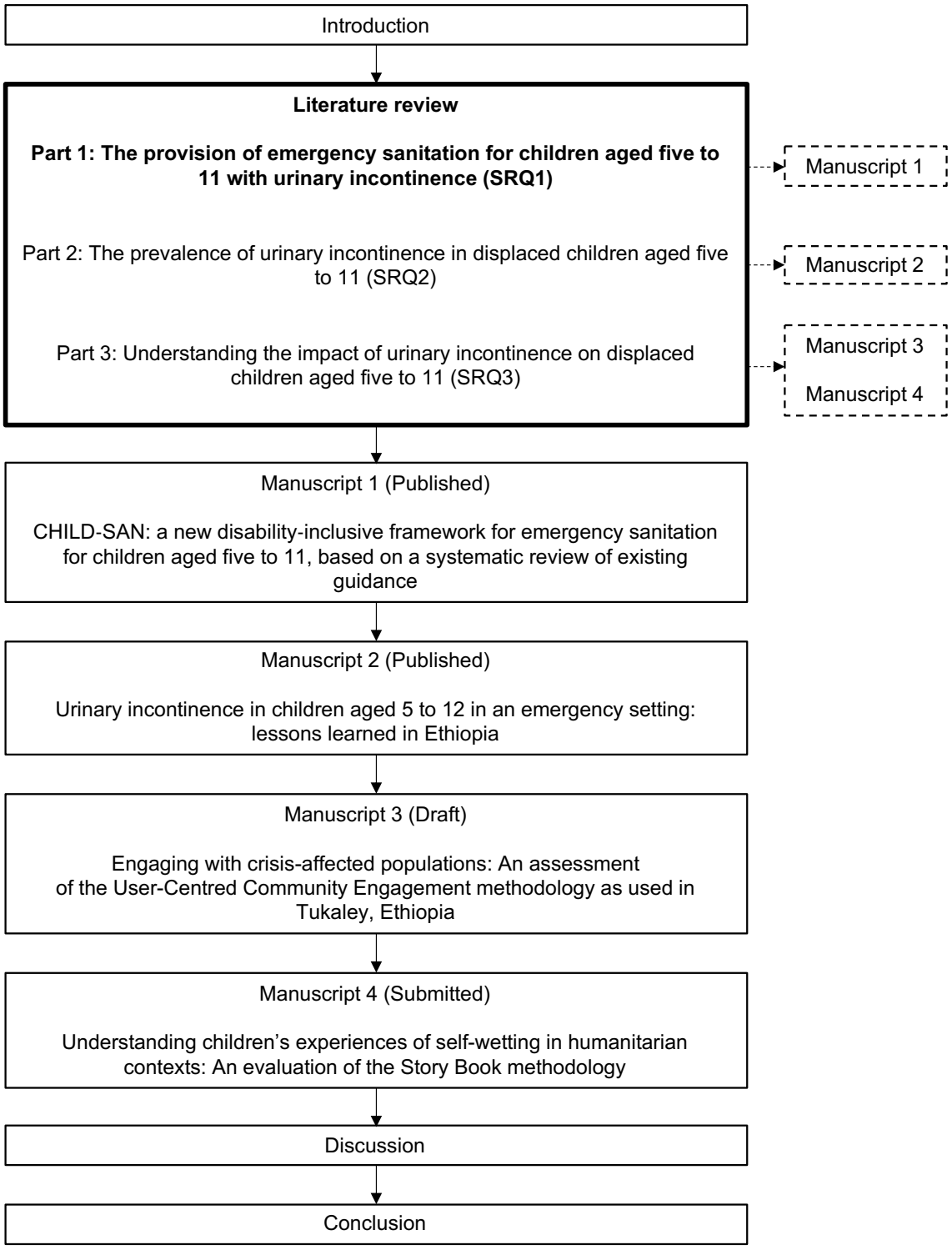
children and their caregivers. It is not known how best to support displaced children that self-wet and their caregivers. These unknowns are worth exploring, and not least due to the vast number of potential beneficiaries. Notably, children have a right to sanitation: all humans are entitled, without discrimination, 'to have physical and affordable access to sanitation, in all spheres of life, that is safe, hygienic, secure, socially and culturally acceptable and that provides privacy and ensures dignity' (United Nations, 2015). Further, displaced children should be supported to 'live with good health, dignity, comfort and safety' (Sphere Association, 2018 p.92) with the WHO defining health as 'a state of complete physical, mental and social well-being' (WHO, 2006 p.1).

This PhD assumes that more children will wet themselves in an emergency context relative to a non-emergency context due to there being a relatively higher proportion of children not wanting, or not being able, to use the sanitation facilities available (particularly at night). It assumes that displaced children who wet themselves, and their caregivers, will experience similar physical, social and emotional impacts as children in non-emergency contexts, and their caregivers, do. This PhD also assumes that the water, sanitation and hygiene (WASH) sector is well-placed to reduce the prevalence of social incontinence in an emergency setting (by providing sanitation facilities that children want, and are able, to use) and to help families with children that self-wet to manage the condition through the provision of at least water and soap.

The Literature Review of this PhD is structured in three parts to explore these assumptions, and each part has an associated journal article(s). Part 1 of the Literature Review (and associated Manuscript 1) reviews the existing literature to better understand UI (causation, treatment and management) and the current provision of emergency sanitation for children aged five to 11 (best practice guidance versus reality). Part 2 (and associated Manuscript 2) aims to determine – for the first time – the prevalence of children wetting themselves in an emergency context using a survey in Tukaley village (Ethiopia). Finally, Part 3 of the Literature Review (and associated Manuscripts 3 and 4) explores how researchers and humanitarian practitioners can better understand the impact of self-wetting on displaced children and their caregivers in order to better meet their needs. Two case studies have been conducted, each using a different methodology specifically designed to be used a) in a humanitarian context, b) with children, and c) on the sensitive issue of toileting behaviours: the User-Centred Community Engagement methodology in Tukaley, Ethiopia; and the Story Book methodology (the design of which was led by the author) used in refugee settlements in Adjumani District, Uganda, and refugee camps in Cox's Bazar, Bangladesh.

To the best of the author's knowledge, the research conducted for the purposes of this PhD in Bangladesh, Ethiopia and Uganda are the first attempts to better understand self-wetting in displaced children aged five to 11, and findings include novel tools and practical recommendations for both researchers and practitioners to improve the provision of emergency sanitation for this age group, including children that wet themselves.

Emergency sanitation for children with urinary incontinence (Rosato-Scott)



Literature Review

Part 1: The provision of emergency sanitation for children aged five to 11 with urinary incontinence

Children and emergencies

The United Nations (UN) Convention on the Rights of the Child (CRC) defines a child as 'every human being below the age of 18 years unless under the law applicable to the child, majority is attained earlier' (Part I, Article 1) (United Nations, 1990) but cultural definitions of the upper limit of childhood may vary. Children are particularly vulnerable in an emergency[3], which is a subjective concept but generally defined as 'a situation that threatens the lives and well-being of large numbers of a population and requires extraordinary action to ensure their survival, care and protection' (UNICEF, 2010 p.4).

At the end of 2020, the UNHCR estimated that there were 93.12 million persons of concern[4] (UNHCR, 2021). Of these, the UNHCR had demographic data on 43.83 million: just under half (20.24 million) were under 18 years of age, and almost 1 in 5 (8.10 million) were aged between five and 11 years of age (UNHCR, 2021). In 2022, the OCHA estimates that '274 million people will need humanitarian assistance and protection' which could include 54.8 million children aged between five and 11 (assuming 1 in 5 are aged between five and 11) (OCHA, 2021 p.9).

Within the disruption of an emergency, children of any age face a range of heightened risks – particularly if separated from family and/or caregivers – including disease, a disrupted education, gender-based violence including sexual violence and exploitation, malnutrition, neglect, physical and emotional abuse, psychosocial distress, trafficking and recruitment into armed groups (Tanner and O'Connor, 2017; Sphere Association, 2018; UNICEF, 2021). They are also dependent on others to provide their needs including safe food and water, shelter and healthcare.

The Core Commitments for Children in Humanitarian Action (CCCs) are a global framework for humanitarian action for children guided by international human rights law

[3]For the purposes of this thesis 'emergency' and 'humanitarian crisis' will be used interchangeably.

[4]Any person whom the UNHCR considers to be a refugee, a returnee, stateless, internally displaced or an asylum-seeker.

(including the Convention on the Rights of the Child and international humanitarian law), and based on global standards and norms for humanitarian action (UNICEF, 2010). The CCCs outline the programme commitments of six sectors for action in the first eight weeks of an emergency response and provide guidance for action beyond that (UNICEF, 2010). One of these sectors is WASH[5].

The WASH sector in an emergency

WASH incorporates water (clean water supply for human consumption and household needs); sanitation (excreta disposal, solid waste management, drainage and vector control) and hygiene (community mobilisation and engagement, information, education and communication, non-food item distributions and health data monitoring) (Oxfam, 2013 p.4). In the first stages of an emergency response WASH interventions aim to prevent and reduce mortality and morbidity by minimising the spread of disease, primarily through the separation of humans and faecal matter. They are 'not necessarily intended to provide long-term sustainable access, but instead provide rapid relief' (Yates et al., 2018 p.32).

The World Health Organization (WHO) recognises four stages of response to an emergency: first steps (normally the first week), emergency response (normally the first month), continuing response/consolidation (beyond the first month) and phasing out/recovery (WHO, 2008). WASH interventions must therefore adapt as the emergency progresses to beyond providing 'rapid relief' in the initial acute response phases. In the continuing response/consolidation phase, efforts should aim to shift from the provision of communal solutions to culturally appropriate and sustainable household-level solutions informed by the equitable participation of the affected population (Gensch et al., 2018). During the phasing out/recovery phase, infrastructure development should continue with the participation of stakeholders increasing to facilitate handover to local and longer-term partners (Gensch et al., 2018).

As the average length of a humanitarian crisis is over nine years (EU Science Hub, 2020), there will be multiple 'emergency' WASH interventions during that time, with differing objectives. The Sphere Handbook (Sphere Association, 2018) is generally considered by the humanitarian sector to be the best practice guidance for the delivery of emergency WASH interventions. Sphere lists that a key activity of emergency WASH

[5]The other five sectors are nutrition, health, HIV and AIDS, education and child protection.

interventions is ‘ensuring conditions that allow people to live with good health, dignity, comfort and safety’ (Sphere Association, 2018 p.92) with the WHO defining health as ‘a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity’ (WHO, 2006 p.1).

The Sustainable Development Goals (SDGs) ask even more of emergency WASH interventions. The SDGs aim to ‘achieve universal and equitable access to safe and affordable drinking water for all’ (SDG Target 6.1) and ‘achieve access to adequate and equitable sanitation and hygiene for all … paying special attention to the needs of women and girls and those in vulnerable situations’ by 2030 (SDG Target 6.2) (United Nations, 2016). Prior to the SDGs, the main priority had been decreasing the proportion of households without access to safe drinking water and basic sanitation; to achieve universal access non-traditional definitions of ‘households’ now need to be considered, including displaced populations (Behnke et al., 2018). The aim must therefore be that in the care and maintenance phases of an emergency, WASH interventions:

- provide universal and equitable access to safe and affordable drinking water for all (United Nations, 2016);
- provide access to adequate and equitable sanitation and hygiene for all, paying special attention to the needs of women and girls and those in vulnerable situations (United Nations, 2016); and
- maximise opportunities for good health (defined as complete physical, mental and social well-being), dignity, comfort and safety (WHO, 2006).

The challenges faced in achieving this are immense, not least being the transient nature of displaced populations. In 2016, the United Nations Children’s Fund (UNICEF) estimated that 31 million children lived outside their country of birth, including 11 million child-refugees and asylum seekers – nearly 1 in every 200 children in the world was a refugee – and 17 million children were internally displaced (UNICEF, 2016). It is ‘difficult to overestimate the perils of children on the move’ (UNICEF, 2016 p.2). as they undertake journeys by land, air and sea to reach new homes. The health of these children will be related to a) their state of health before the journey, b) the risks faced during all phases of the journey, c) the risks faced in settlements, and d) the health of caregivers (WHO, 2018a).

Urinary incontinence in children: Definitions

Urinary incontinence (UI) is the involuntary leakage of urine[6]. It can be classified as anatomic (related to the structure of the body, congenital – from birth – or acquired), neurologic (a disorder of the nervous system, congenital or acquired), or functional (bodily functions are impaired) (Schaeffer and Diamond, 2014).

The International Children's Continence Society (ICCS) defines several UI subdivisions for children (Table 1).

Table 1 Urinary incontinence subdivisions for children *(Austin et al., 2016)*

Subdivision	**Description**
1. Continuous urinary incontinence	Constant leakage of urine
2. Intermittent urinary incontinence	Intermittent leakage of urine
2.1 Daytime urinary incontinence (DUI)	Discrete leakage of urine when awake
2.2 Enuresis	Discrete leakage of urine when asleep
2.2.1 Monosymptomatic enuresis (MNE): primary or secondary	Enuresis without any other lower urinary tract (LUT) symptoms and without bladder dysfunction Primary MNE: occurs without a previous dry period Secondary MNE: occurs after a dry period of more than six months
2.2.2 Non-monosymptomatic enuresis (NMNE): primary or secondary	Enuresis with any other LUT symptom. See Appendix A1 for further details. Primary NMNE: occurs without a previous dry period Secondary NMNE: occurs after a dry period of more than six months
2.3 Daytime urinary incontinence and enuresis	Discrete leakage of urine when awake and asleep

Not all children who wet themselves (in the day and/or at night) will be considered to have the *medical condition* of urinary incontinence. To be medically diagnosed as having the condition, the following criteria must be met:

[6]Urination is also known as micturition.

- For the symptom of **DUI** to be a medical condition, the American Psychiatric Association, the ICCS and WHO require a minimum age of five years, and a minimum of one episode per month for a minimum duration of three months (American Psychiatric Association, 2013; Austin et al., 2016; WHO 2018).
- **Enuresis** is clinically significant if a) the child is at least five years old (or equivalent developmental level); b) it is not exclusively due to the effects of taking a substance (i.e. a diuretic, which is a substance that promotes the increased production of urine) or a general medical condition; and c) the frequency is at least twice weekly for at least three consecutive weeks, and/or it is accompanied by significant distress and/or impairment in areas of functioning (for example, social and academic) (American Psychiatric Association, 2013). The ICCS further qualifies the significance of enuresis as frequent (more than four times per week) or infrequent (less than four times per week) (Austin et al., 2016).

The American Psychiatric Association, the ICCS and WHO define five years as the minimum age for DUI and enuresis to be clinically significant as it is deemed to be the developmental age when urinary continence is ordinarily expected. There are cultural differences in expectations of continence and subsequently the age at which toilet training is initiated and completed. Mota and Barros' (2008) literature review found that in many countries the age of initiation is increasing and that white children in the United States were the last to complete toilet training (at 39 months). These findings were echoed by van Aggelpoel at al.'s (2017) study which also found that the age of initiation is increasing (to up to 30 months) and that it is higher in Western cultures compared to African, Asian and Latin American. For the purposes of this thesis, urinary incontinence will be defined as medically significant from the age of five years, in line with guidance, and higher than parental expectations of continence. It is noted however that child distress and/or parental concern will affect the significance of any UI condition in a child at any age.

The causes of UI in children

a) Causation: DUI

Functional UI is incontinence not caused by congenital malformation, disease or injury; that is, there is no obvious cause (Hjälmås, 1992), although a number of independent risk factors have been identified (Table 2).

Table 2 DUI: Independent risk factors

Independent risk factor	**Notes**
Enuresis	Enuresis has been identified as an independent risk factor for DUI (Abrams et al., 2017)
Female gender	Buckley and Lapitan (2010) found a higher prevalence of DUI in girls from the age of 11. Abrams et al. (2017) also found a higher prevalence of UI (DUI, and DUI and enuresis) in older girls Also: Sureshkumar *et al.*, 2000
Paternal familial history of DUI and/or enuresis	Sureshkumar et al., (2000) found a significant association with a history of DUI among male siblings and/or in the paternal lineage Also: Buckley and Lapitan, 2010; Abrams *et al.*, 2017
Defecation dysfunction (for example, faecal incontinence with or without constipation)	The urodynamic and anodynamic organ systems are interdependent and therefore conditions that affect one may affect the other (Feng and Churchill, 2001). Constipation and bowel distension may also lead to bladder deformation and subsequently to UI due to hyperactivity of the detrusor muscle (which when contracted, pushes urine out of the bladder) (Koff et al., 1998) Also: Kajiwara *et al.*, 2004; Söderstrom *et al.*, 2004; Loening-Baucke, 2007; Buckley and Lapitan, 2010; Esezobor, Balogun and Ladapo, 2015; Abrams *et al.*, 2017
History of urinary tract infections (UTIs)	Sureshkumar et al., (2000) found that although UTIs were twice as common in children with DUI, the majority of children with DUI did not have a history of UTIs. Hjälmås (1992) also found a strong association between UTIs and DUI in girls, but cause and effect may work in both directions; Abrams et al., (2017) believe that UTIs are a consequence of DUI Also: Kajiwara *et al.*, 2004

b) Causation: Enuresis

Enuresis is due to:

1. Relative nocturnal polyuria (an increased volume of urine in the bladder);

The circadian rhythm of urine production reduces nocturnal volumes to around 50% of daytime levels. This is due to the nocturnal release of hormones that increase urine concentration and decrease urine production. Around two thirds of younger children with MNE lack a circadian rhythm of the hormone arginine vasopressin (AVP) which regulates free water excretion. This results in high nocturnal urine production that exceeds bladder capacity. In adolescents, relative nocturnal polyuria is no longer due to a diurnal rhythm of AVP production, but a lack of sensitivity to it (Abrams et al., 2017). Recent literature suggests that other alterations to the renal circadian rhythm may also play a role, for example, renal solute handling (Dossche et al., 2016).

2. *and/or* nocturnal bladder overactivity;

   If the detrusor is not relaxed during filling it results in a decreased functional bladder capacity and small voided volumes (Abrams et al., 2017).

3. *combined with* a lack of arousal.

   A lack of arousability, that is a child will not wake-up when they need to urinate, differentiates children with enuresis and nocturia (Abrams et al., 2017).

The following independent risk factors have been identified (Table 3):

Table 3 Enuresis: Independent risk factors

Independent risk factor	**Notes**
DUI	DUI has been shown to be the strongest predicator for enuresis (Abrams et al., 2017)
Age	Prevalence decreases with increasing age, with spontaneous cure rates of around 15% annually between 7 and 12 years, and 11% annually between 12 and 17 years (to a prevalence of 0.5-1.7% by age 16-17 years). (Morison, Staines and Gordon, 2004; Abrams *et al.*, 2017) Also: Mattsson, 1994; Lee *et al.*, 2000; Kanaheswari, 2003; Yeung *et al.*, 2006; Esezobor, Balogun and Ladapo, 2015

Male gender	Buckley and Lapitan (2010) found a higher prevalence in boys decreasing with age (as high as 2:1 in Western studies noting that ethnic differences were unclear) Also: Akinyanju *et al.*, 1989; Mattsson, 1994; Kanaheswari, 2003; Morison, Staines and Gordon, 2004; Butler, Golding and Northstone, 2005; Esezobor, Balogun and Ladapo, 2015; Abrams *et al.*, 2017
Familial history of enuresis	Piyasil and Udomsup (2002) found that 16.0% of Thai children aged 5 to 15 years with enuresis had siblings with enuresis, and 14.0% of children aged 5 to 15 years with enuresis had a parent with a history of enuresis. Fockema et al., (2012) found that 22.4% of South African children aged 5 to 10 years with MNE had at least one sibling or parent with a history of MNE. Abrams et al., (2017) found that the age to spontaneous resolution was also familial Also: Morison, Staines and Gordon, 2004; Buckley and Lapitan, 2010; Esezobor, Balogun and Ladapo, 2015; Makrani *et al.*, 2015; Esezobor *et al.*, 2018
Defecation dysfunction (for example, faecal incontinence with or without constipation)	Fockema et al., (2012) found that 15.8% of South African children aged 5 to 10 years with MNE had constipation Also: Esezobor, Balogun and Ladapo, 2015
Other	Many other independent risk factors have been identified, including developmental delay, mental retardation, low birth weight, perinatal events such as toxaemia, attention deficit hyperactivity disorders, minor neurological dysfunction, high liquid intake, parents socio-economic level, presence of sniffing and mouth breathing, obstructive sleep apnoea, sickle cell disease, sexual abuse, corporal punishment, difficulty in arousal from sleep and refugee status (Akinyanju et al., 1989; Morison et al., 2004; Buckley and Lapitan, 2010; Anderson et al., 2014; Makrani et al., 2015; Abrams et al., 2017; Esezobor et al., 2018; Jurković et al., 2019)

The treatment of UI in children

a) Treatment: DUI

Urotherapy is the conservative treatment of DUI. It encompasses a broad range of non-surgical and non-pharmacological interventions that require little input from health professionals, and which can be employed in isolation or in combination (Buckley et al., 2019). Any treatment programme should begin by ensuring that the caregiver understands the abnormalities of the child's LUT function (demystification), and the aims of the treatment (Deshpande et al., 2012). Constipation should also be addressed (to reduce the pressure on the bladder) before beginning any intervention.

Simple lifestyle and behavioural interventions include:

a) Education regarding diet, including the reduction of aggravating agents such as caffeine;
b) Education regarding fluid intake;
   The optimal fluid intake is 50ml/kg/day up to 2.5l/day maximum (Deshpande et al., 2012)
c) Education regarding regular voiding;
   Optimally, 5-7 times per day without straining (Deshpande et al., 2012)
d) Education regarding toilet posture;
   To develop and heighten a child's awareness of the correct voiding processes, and encourage taking the time to void
e) Bladder diaries to establish voiding patterns (and subsequently a voiding schedule);
   To include the frequency and volume of fluid intake, urinations and incontinence episodes
f) Toilet plans and scheduled voiding; and
   To retrain the bladder and brain into a new pattern and to suppress urges. Using a reminder watch or alarm may increase adherence (Hagstroem et al., 2010)
g) Incentives and rewards.

More complex lifestyle and behavioural interventions to increase bladder capacity (and which require the increased involvement of healthcare professionals) include:

a) Bladder training (also known as bladder drill, discipline, or re-education);

To increase bladder capacity by deliberately increasing the time between the urge to void and voiding; and

b) Double voiding (to ensure that the bladder is empty) (Buckley et al., 2019).

Conservative treatment can also include physical interventions, which again require the increased involvement of healthcare professionals:

a) Pelvic floor muscle training (to strengthen and/or relax the muscles);
b) Abdominal muscle training / core stability exercises, with or without biofeedback[7] (to improve the tone of muscles that support continence); and
c) Transcutaneous (applied to the skin) electrical stimulation of the sacral root or tibial nerve (Buckley et al., 2019).

Urotherapy is the foundational treatment for DUI and it has a higher success rate than the condition's natural course: the European Bladder Dysfunction Study found that approximately 40% of children with DUI could be cured with standard urotherapy alone versus an annual cure rate of 10-15% (Bachmann et al., 2008; Chang et al., 2017). If urotherapy is not successful, treatment can progress to pharmacological and/or surgical interventions.

b) Treatment: NMNE

As with DUI, the treatment of NMNE should begin with the demystification of the condition. Any constipation or UTIs should then be treated, followed by the treatment of the LUT disorder. This should include those simple lifestyle and behavioural interventions listed above. If still necessary, the enuresis can then be treated. The recommended treatment is generally the use of an alarm (about two thirds of children become dry), and/or the drug desmopressin[8] (30% children fully respond) (Franco et al., 2013). If this treatment is not effective, further medical research is required.

[7]Biofeedback is the use of auditory or visual signals to increase the awareness and control of muscle relaxation and contraction, which improves the effectiveness of muscle training (Buckley et al., 2019). Note that a systematic review of randomised control trials did not find a significant difference in the proportion of children with no improvement in DUI when using biofeedback versus not (Sureshkumar et al., 2003).

[8]An antidiuretic which reduces the amount of urine produced at night.

c) Treatment: MNE

Again, treatment should begin with the demystification of the condition, and the treatment of any constipation or UTIs. Simple lifestyle and behavioural interventions listed above may be applicable, but generally the recommended treatment is the use of an alarm and/or the drug desmopressin.

The management (in the absence of treatment) of UI in children

Despite the treatment options available, medical help is often not sought by carers:

- of 280 Nigerian children with enuresis or DUI, the parents of only nine consulted a medical professional about the condition. This was despite a median score of 5 (of a scale of 1 to 10) regarding their level of worry about enuresis (Esezobor et al., 2015);
- Sureshkumar et al., (2000) found that only 16% of Australian families with children with DUI had sought medical assistance, with a significant linear trend in the proportion of help-seekers related to the severity of the wetting. A similar help-seeking pattern was found by Bower et al. (1996) for Australian families of enuretic children;
- Schlomer et al., (2013) found that only 55% of American parents would seek medical advice for an enuretic child.

This could be due to, for example:

- a belief that UI is ‘normal’: Yeung et al. (2006) found that an increase in the awareness of enuresis due to a public health educational programme in Hong Kong resulted in an increase in enuretic patients; and Can et al. (2004) found that parents believed enuresis to be ‘normal’ due to the prevalence of enuretic relatives;
- a lack of awareness of the treatment options available (‘nothing can be done’): Fockema et al. (2012) found that 42% of South African parents with children with MNE were unaware of specific treatments for the condition; and/or
- an underestimation (or trivialisation) of the impact of the condition on the child.

In such cases, UI can be managed using products and aids (such as a) disposable inserts, pads or diapers, b) reusable cloth and c) mattress protectors) and caregivers may pursue remedial strategies including fluid retention and voiding delay, incentive measures, traditional practices and psychotherapy (Chao et al., 1997). Unfortunately, management strategies can also include punishment.

Morison (1998) found that parental attitudes towards their child's enuresis were determined by a) their definition of enuresis as (in)appropriate for the child's age; b) the extent to which they regarded the condition as a cause for concern; c) their beliefs about the child's capacity to control the condition; and d) their beliefs in their own capacity to influence the situation. Three categories of parental attitudes were found: 1) acceptance and tolerance, due to a belief that the child is not yet able to control their bladder at night; 2) ambivalence, as the condition can only be changed by the child; and 3) rejection and intolerance, as the condition is within the child's control but is not being resolved (Morison, 1998). Schober et al. (2004) also found that although most parents approached enuresis with tolerance, this can decline with the increasing age and maturity of the child as expectations of levels of responsibility and self-control increase.

Morison (1998) found that parents responding with rejection and intolerance were experiencing frustration and anger, with many also having to cope with other problems at the same time ('stress pile-up'). Perhaps this is why Schober et al. (2004) found that parents from migrant populations, who may be experiencing 'stress pile-up', appeared less tolerant. Frustration and anger can manifest in punishment. In a study conducted in Turkey, Can et al. (2004) found that 86.4% of parents with enuretic children were involved in child abuse, defined as spankings, beatings, medical neglect and/or swaddling; and in Brazil Sapi et al. (2009) found that 89% of enuretic children suffered abuse characterised by verbal punishment associated or not with other types of aggression. Such a response will have a negative impact on the child, both in terms of their response to medical treatment for enuresis (Ferrara et al. (2016) found that at least one punishment was given to 27 of 218 enuretic children which reduced their response to treatment) and on their long-term mental health: Schober et al. (2004) found that an enuretic child that is not provided with comfort may experience shame, embarrassment, loneliness, isolation, frustration and distress.

Chao et al. (1997) found that those parents that did eventually seek medical treatment did so due to restricted outdoor activities (90%), parental fatigue (86.7%), disrupted household sleep (46.7%) and/or fear of underlying disease (26.7%).

The treatment and management of UI in children during an emergency

No reference to a study to determine how UI in children is treated and/or managed in an emergency setting was found during the literature review or during the interactions with

experts throughout this PhD (Appendix A2). Only one reference to the treatment of bedwetting in children was noted, in the Zaatari refugee camp located in Jordon:

> "*any child over the age of 5 who wets themselves still at night are put on a form of psychosomatic treatment. And to reinforce this treatment apparently they are not allowed to have a nappy at night time*" (Veneme, 2015).

Only one mention of management strategies for UI in children was found, in a paper summarising the healthcare needs of transiting refugees in Greece:

> *"Even when access (to water) was good – for example, in the camps and on the ferry – people deliberately restricted their water intake to avoid frequent stops for toilet visits and nocturnal incontinence in young children. The idea of temporary sacrifice in order to achieve the end goal of reaching your destination was often seen as the lesser of two evils"* (Shortall *et al.*, 2017 p.276).

Social incontinence in children

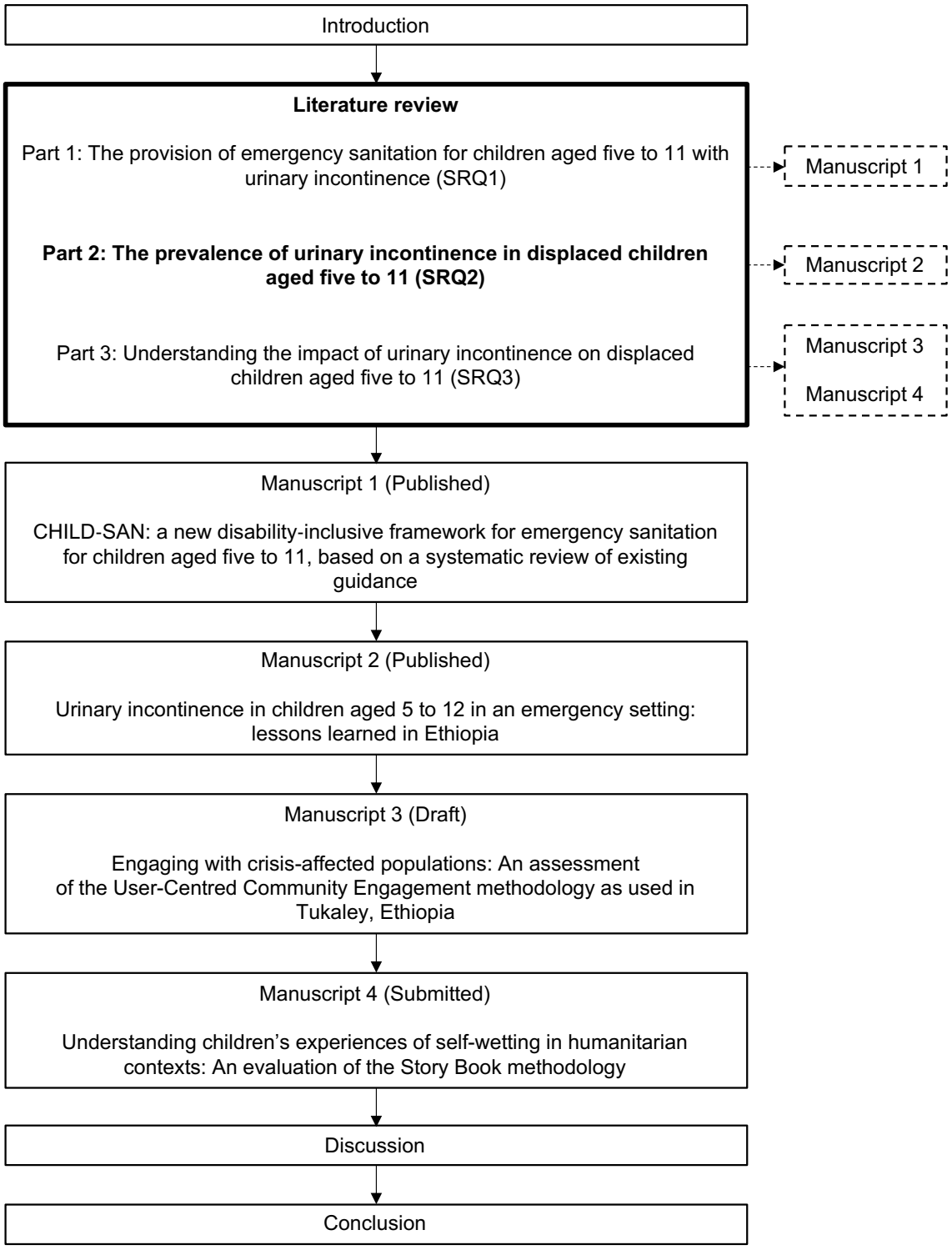
Sometimes children may not want to use, or not be able to use, the sanitation facilities available, for example, at night in a refugee camp. They may therefore urinate elsewhere, including on themselves. This has been termed 'social incontinence' and it is not a medical condition (Ryan, 2018).

When the cause of a child wetting themselves is unknown (that is, it could be due to them experiencing the medical condition of urinary incontinence or social incontinence), the term self-wetting can be used.

All children that experience self-wetting have significantly increased needs for water supply and for accessible, private WASH facilities (Rosato-Scott et al., 2020). The provision of emergency sanitation for children aged five to 11, and including children with UI, therefore needs to be explored.

Please note that Manuscript 1 (CHILD-SAN: a new disability-inclusive framework for emergency sanitation for children aged five to 11, based on a systematic review of existing guidance) is associated with Part 1 of the Literature Review.

Emergency sanitation for children with urinary incontinence (Rosato-Scott)



Part 2: The prevalence of urinary incontinence in displaced children aged five to 11

Baseline prevalence of UI in children aged five to 11

It is difficult to determine a baseline prevalence of UI in children. Numerous studies have been completed, but comparison is rarely possible due to a lack of homogeneity in study design including definitions, study population, means of sampling and enrolment, and methods of data collection. A systematic literature search for systematic reviews of prevalence studies was completed on 9 November 2021. A review of the grey literature also resulted in three relevant items (Morison, Staines and Gordon, 2004; Buckley and Lapitan, 2010; Abrams *et al.*, 2017). See Appendix A6 for methodology and results.

The reviews found that the prevalence of DUI in children decreases with age, from 2.0-9.0% in seven year olds, to 1.1-12.5% in 11 to 13 year olds, to 1.1-3.0% in 15 to 17 year olds (Buckley and Lapitan, 2010). For the purposes of this study a baseline DUI prevalence of 2.0-9.0% in children aged five to 11 will therefore be assumed.

Makrani et al., (2015) estimate a prevalence of NMNE in Iranian children aged five years and older at 11.01% (being boys at 13.9% and girls at 8.4%). However, both Buckley and Lapitan (2010) and Abrams et al., (2017) concluded that it is more appropriate to calculate the prevalence of enuresis for an age cohort rather than an age range as bladder control develops throughout childhood. Abrams et al., (2017) found that most studies reported a prevalence of any enuresis of 7.0-10.0% at seven years of age, albeit higher frequencies were reported in studies conducted in Turkey (15.1%), Korea (16.4%) and Yemen (31.0-45.0% in children aged 6 to 8 years). At 11 to 12 years prevalence was found to have decreased to 1.7-4.8%, falling further to 0.5-1.7% by age 16-17 years (Abrams et al., 2017). Buckley and Lapitan (2010) found that studies consistently reported a prevalence of MNE of 6.2-7.4%, and of NMNE of 6.8-16.4% at seven years of age. Morison, Staines and Gordon (2004) found that the prevalence of NMNE decreases with age, from 15.0-20.0% in five years olds to 5.0-10.0% in seven year olds, to 1.0-3.0% in adults in Asia, Australia, Europe, New Zealand and United States, corresponding with the maturation of night-time bladder control. For the purposes of this study a baseline enuresis prevalence of 5.0-20.0% in children aged five to 11 will therefore be assumed.

A systematic review of prevalence studies of children with both DUI and enuresis was not found. Abrams et al., (2017) commented that although a number of studies found

that the prevalence of both also decreases with age (from 3.2-11.2% in seven year olds, to 0.9-12.5% in 11 to 13 year olds), differences in study design may impact the wide range of findings.

Prevalence of UI in displaced children aged five to 11

The impact of stress and trauma on prevalence

A systematic literature review did not reveal any studies that determine the prevalence of UI in children aged five to 11 in an emergency setting (see Appendix A3), although anecdotally bedwetting and DUI have been observed (Veneme, 2015; Save the Children, 2016; Farrington, 2019). Prevalence rates in an emergency context may be impacted due to the presence of environmental factors, and particularly stress and trauma.

Although some studies report a higher prevalence of **DUI** in children under stress, the direction of the causal relationship between psychological problems and DUI was found to be unclear (Sureshkumar *et al.*, 2000; Buckley and Lapitan, 2010; Abrams *et al.*, 2017)

Recent advances in understanding the female pelvic floor suggest that it is the tightness of pelvic structures, not weakness, which can cause organ misalignment and subsequently bladder dysfunction. This is based on the concept that the human body is a tensegrity structure (biotensegrity) within which the muscoskeletal system is suspended within and supported by fascia (connective tissue). This tissue accommodates changes in tensional demands due to, for example, stresses and strains, by contracting or stiffening. Within the pelvic biotensegrity structure, disruptions to the fascia can pull organs into a place of discomfort or reduced functionality. Releasing the tension within the pelvic fascia can restore the equilibrium and result in a return to healthy pelvic organ alignment (Crowle and Harley, 2020). Injury to tissue due to physical trauma, for example, is known to result in contracted fascia. However research has yet to prove a link between emotional stress (in this instance being the release of adrenaline[9] and/or acetylcholine[10]) and fascial tension (Schleip, 2019).

Stress and anxiety have been found to contribute to the etiology of **primary enuresis** (Keith, 1968; Joinson et al., 2016). Joinson et al., (2016) concluded that the risk of experiencing problems attaining bladder control at four to nine years of age is greater if the child has been exposed to stressful events in the first four years of life, but noted that

[9]A hormone produced when under stress.

[10]A neurotransmitter released when under mild stress.

it is the total burden of stress rather than the specific event that is the determinant. For example, Jones et al., (2003) found that enuresis (and usually primary enuresis) was the most common reason (15.8%) for attendance at a child and adolescent mental health service located in Kosovo, two years after the cessation of NATO airstrikes. Joinson et al., (2016) also found that increasing levels of exposure to early stress are associated with increasing severity (frequency and persistence) of enuresis.

Exposure to stressful events or life changes also increases the risk of **secondary enuresis**, although this association may be bidirectional (Järvelin et al., 1990; Joinson et al., 2016). Fockema et al., (2012) found that 29.4% of South African children aged five to 10 years with MNE had a link to stress, defined as a serious injury to the child or other family member, illness in the family, violence to the child or other family member, death in the family, parental divorce or separation or other reason including a strict parent or teacher, bullying, birth of a sibling, and moving house. Järvelin et al., (1990) found that separation from a parent had the most significant effect on the occurrence of enuresis; Lind (2018) commented that enuresis was noted as a typical change in behaviour in children separated from parents at the US-Mexico border in 2018; and Jurković et al. (2019) identified refugee status as a risk factor in the occurrence of enuresis in children likely due to the cumulative stresses and traumatic experiences of displacement and forced movement. Although a distinction between primary or secondary enuresis was not provided in these studies, it can be assumed that both conditions were present given the age of the cohorts.

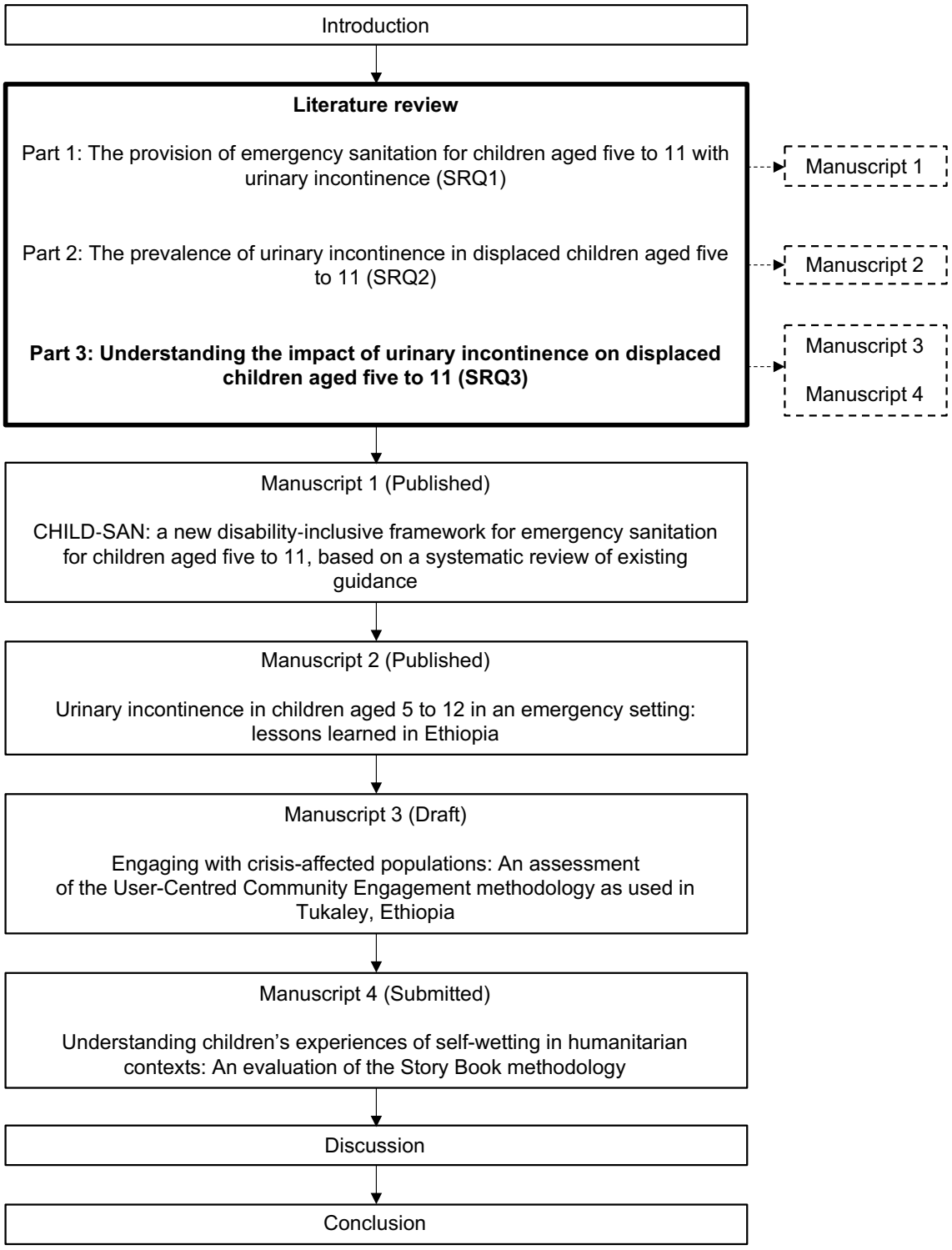
It is also hypothesised that a child is vulnerable to bladder dysfunction due to stress if the transition to continence is impacted. That is, stress at the time of toilet training impacting the child and/or caregiver, results in a delayed, inadequate or prolonged transition. The stress hormone cortisol also suppresses the release of antidiuretic hormones, resulting in polyuria (Järvelin et al., 1990; Joinson et al., 2016).

The impact of social urinary incontinence on prevalence

Social urinary incontinence can occur when a child has full control of their bladder, but lacks the ability to urinate because there isn't a suitable place to use (Ryan, 2018). For example, at night in a refugee camp a child may not want to use (or be fearful of using) a public latrine and instead urinate in their dwelling. This may contribute to anecdotes of high numbers of children bedwetting (Veneme, 2015; Farrington, 2019).

Please note that Manuscript 2 (Urinary incontinence in children aged 5 to 12 in an emergency setting: lessons learned in Ethiopia) is associated with Part 2 of the Literature Review.

Emergency sanitation for children with urinary incontinence (Rosato-Scott)



Part 3: Understanding the impact of urinary incontinence on displaced children aged five to 11

What is known about the experiences of children aged five to 11 with UI, and their carers

Physical impact

Children with urinary incontinence may experience skin rashes (incontinence associated dermatitis which is similar to nappy rash) and/or urinary tract infections (Great Ormond Street Hospital, 2017). If fluid intake is restricted to limit the need to urinate then the child may also become dehydrated.

Social and emotional impact

The social and emotional effect of the condition on daily life can also be significant. Unfortunately, “links between the bladder and the soul are difficult to disentangle” and knowing what is an effect (rather than a cause, or a comorbidity without a direct causal relationship) is difficult (Nevéus, 2011 p.1209).

a) Children with DUI

Societies develop rules of acceptable elimination behaviour and these cultural values become strongly internalised. When children are taught compliance through shame and embarrassment, public wetting can become associated with ‘being bad’. In such cultures, the child can also be subject to gossip, hostility and ostracism (Garcia et al., 2005). A number of studies have therefore researched whether children with DUI suffer psychological distress, but many have limitations and findings have been non-conclusive.

For example, Joinson et al.'s (2007) study found higher levels of psychological distress in children with UI than without, with rates of attention, oppositional and conduct problems in children with both DUI and enuresis more than twice those in children without leakage. Given the public nature of DUI, the study also found a higher-rate of externalising and internalising problems in children with both DUI and enuresis than for enuresis children only (with the exception of social fears and sadness/depression). However, this was based on the parent-reported data and there

was little evidence from the children's own reports to suggest that children with leakage had more problems than those without (Joinson et al., 2007).

b) Children with enuresis

Anecdotes about children with enuresis reveal feelings of humiliation, shame and guilt; avoidance of social activities; a sense of feeling different; victimisation; and a loss of self-esteem (Butler and Heron, 2007). Empirical support of such accounts is equivocal, largely due to a lack of homogeneity in study design and the difficulties in interpreting research findings. The weight of evidence suggests that children with enuresis view the condition as a social phenomenon rather than a health problem and whilst they are not psychologically disturbed, some may be more psychologically vulnerable including those with severe enuresis, secondary enuresis and/or DUI (Butler and Heron, 2007). Studies have also found that self-esteem improves after successful treatment (Theunis et al., 2002), yet Grzeda et al. (2017) found that previous UI in childhood is associated with increased levels of psychosocial problems in adolescence including poorer self-image and problems with peer relationships.

c) Carers

There will also be implications for the carers of urinary incontinent children. Having multiple sets of bedding and clothes to wash is demanding physically and financially (if soap and water need to be purchased), particularly in low-resource and emergency settings. The time needed for washing and drying may also limit a caregiver's ability to socialise or participate in income-generating activities. For a co-sleeping family particularly, enuresis can be disturbing for the whole family (Mathew, 2010). In the Zaatari refugee camp in Jordon, NGO worker Peake found that "*the children are really suffering … the problem is that the mothers have been trying to cope for so long that basically they've given up. Night after night of urine and they can't keep them clean*" (Veneme, 2015).

There may also be social and emotional impacts as previously detailed. Management strategies can also include punishment: as a reminder, Can et al. (2004) found that 86.4% of parents with enuretic children were involved in child abuse and Sapi et al. (2009) found that 89% of enuretic children suffered abuse characterised by verbal punishment associated or not with other types of aggression. Such a response will have a negative impact on the child, both in terms of their response to medical treatment and on their long-term mental health.

How to better understand the health experiences of displaced children with UI

Little is known about how displaced children understand and experience health. Hirani and Richter (2019) found limited literature on the effects of forced displacement on child health; Spencer et al. (2019) found that there is a "distinct paucity of (migrant) research that takes children's perspectives as its starting point" and that children as a distinct group are "notably less visible" in published migrant research (p.98). Migrant research to date has tended to prioritise adult frames of reference, including caregiver's perspectives on children's health-related experiences and needs even though adults do not necessarily make good proxies for children (Curtis et al., 2018; Spencer et al., 2019). When using a more holistic definition of health than merely the absence of disease or infirmity, that is as "a state of complete physical, mental and social well-being" (WHO, 2006), it becomes even more crucial to consult with children to fully understand their health experiences.

Operational challenges to conducting research in humanitarian contexts

It is difficult to conduct research in a humanitarian setting. Such contexts – at least in the initial stages – are characterised by disruption and instability which present unique challenges to researchers. These include securing adequate resources (financial, technical, human and time), difficulty in accessing study populations, interruptions to public services, and the inappropriateness of traditional research methods (Dahab, 2017; Leresche et al., 2020). Despite efforts by both academics and humanitarian practitioners in recent years to conduct more research in humanitarian settings, there is still a noted lack of research in such contexts (Leresche et al., 2020). Those responding to a crisis focus (usually) limited resources instead on the immediate needs of the affected population, designing programmes based on anecdotal experience rather than being evidence-led (Kohrt et al., 2019).

Researchers are beginning to share field experiences on *how* research has been conducted in humanitarian settings (notably Mistry et al., 2021). As a result, strategies to address the challenges of conducting research in humanitarian contexts are being suggested, and these include:

- Using flexible, adaptive and iterative methodologies that produce quick, real-time data;
- Collaboration between academic institutions (experienced in research design and analysis) and humanitarian organisations (with established local

relationships, to help address logistical and security challenges, and to ensure that research findings will benefit the affected populations);
- Engagement with affected populations to enable trust, improve research design and facilitate the dissemination of findings; and
- Partnerships with (and leadership by) local actors (including communities, governments, NGOs and academics) (Kohrt et al., 2019; Shahabuddin et al., 2020; Mistry et al., 2021).

Ethical challenges to conducting research with displaced children

Much has been written on the importance of children participating in research (both formative and academic) in all contexts, and the benefits of doing so for both the participants and researchers (O'Kane, 2013a). However in some contexts, the principle of participation may be over-ridden by other principles such as 'do no harm', preventing the realisation of such benefits (Bennouna et al., 2017). Researchers can feel particularly overwhelmed in humanitarian contexts where children of any age and ability face a range of heightened risks – particularly if separated from family and/or caregivers – including disease, a disrupted education, gender-based violence including sexual violence and exploitation, malnutrition, neglect, physical and emotional abuse, psychosocial distress, trafficking and recruitment into armed groups (Tanner and O'Connor, 2017; Sphere Association, 2018; UNICEF, 2021).

An awareness of this vulnerability of children inevitably – and rightly – results in those involved in humanitarian response to emphasise the protection of children (a protectionist discourse). Yet there has been a push in recent years to consider children as rights-holding individuals as well (a rights-based discourse) (Ruiz-Casares et al., 2016). The United Nations Convention on the Rights of the Child (UNCRC) is "an international human rights instrument that provides a framework of common, universally agreed-upon standards" (CP MERG 2012 p.16). The UNCRC is a rights-based framework, and the right of children to be heard and to be taken seriously (Article 12) is one of its four general principles (United Nations, 1990). Further, Paragraph 125 of General Comment Number 12 on 'the right of the child to be heard' states that this right "does not cease in situations of crisis or in their aftermath" (United Nations Committee on the Rights of the Child, 2009).

Although the term 'participation' does not appear in Article 12, the concept has emerged to describe efforts to implement a child's right to be heard (United Nations Committee on the Rights of the Child, 2009). Participation can be defined as "'having the opportunity to

express a view, influencing decision making and achieving change", with children's participation "an informed and willing involvement of all children, including the most marginalised and those of different ages and abilities in any matter concerning them directly or indirectly" (O'Kane, 2013b p.9). The UN Committee on the Rights of the Child summarises the benefits of participation as "helping children to regain control over their lives, contributing to rehabilitation, developing organisational skills and strengthening a sense of identity", but caveats that "care needs to be taken to protect children from exposure to situations that are likely to be traumatic or harmful" (United Nations Committee on the Rights of the Child 2009 Paragraph 125). Consequently, General Comment Number 12 states that to be effective, ethical and meaningful, "all processes in which a child or children are heard and participate, must be 1. Transparent and informative; 2. Voluntary; 3. Respectful; 4. Relevant; 5. Child-friendly; 6. Inclusive; 7. Supported by training; 8. Safe and sensitive to risk; and 9. Accountable" (United Nations Committee on the Rights of the Child 2009 Paragraph 134).

Key documents have subsequently emerged on how to conduct effective, ethical and meaningful research with children. These include the UNICEF Procedure for Ethical Standards in Research, Evaluation, Data Collection and Analysis which reflects international ethical standards (adopting a rights-based approach) and organisational knowledge (UNICEF, 2015). It is guided by three core ethical principles: respect (valuing children and the context of their lives, and recognising their dignity); benefit (non-maleficence or do no harm, and beneficence or the promotion of well-being) and justice (treating children fairly and equitably) (Graham et al., 2013).

Reflecting these notions, the UNICEF Procedure states four core ethical issues when conducting research with children: 1. Harms and benefits; 2. Informed consent; 3. Privacy and confidentiality; and 4. Compensation and payment (UNICEF 2015 p.7). Additional ethical issues specifically related to conducting research with children in humanitarian settings have also been identified in the literature: 5. Institutional capacity to ethically involve children in research; 6. Understanding power relations; and 7. Communication of results (Berman et al., 2016). Together these ethical issues reflect all of the nine basic requirements for participation except relevance, which must also be included when considering the participation of children in research in a humanitarian setting (Table 4).

Table 4 Ethical issues when considering the participation of children in research in a humanitarian setting

Ethical issue (EI) when considering the participation of children in research in a humanitarian setting	**EI reference**	**Source of ethical issue**	**Corresponding basic requirements for participation (United Nations Committee on the Rights of the Child 2009 Paragraph 134).**
Harms and benefits	EI 1	(UNICEF 2015 p.7)	Safe and sensitive to risk
Informed consent and capacities of individuals	EI 2	(UNICEF 2015 p.7) (Berman et al., 2016)	Child-friendly Inclusive Voluntary
Privacy and confidentiality	EI 3	(UNICEF 2015 p.7)	Respectful
Compensation and payment	EI 4	(UNICEF 2015 p.7)	
Institutional capacity to ethically involve children in research	EI 5	(Berman et al., 2016)	Supported by training
Understanding power relations	EI 6	(Berman et al., 2016)	Child-friendly Inclusive Supported by training
Communication of results	EI 7	(Berman et al., 2016)	Accountable Transparent and informative
Relevance	EI 8	Not applicable	Relevant

Introduction to case studies on how to address the challenges of conducting research with displaced children

Two case studies have been provided on research methodologies that have been specifically designed to address the challenges of conducting research with displaced children.

Case Study One addresses the operational challenges of conducting research in humanitarian settings with displaced children, using the User-Centred Community Engagement methodology (UCCE) in Tukaley, Ethiopia. A full description of the UCCE methodology has been provided in this Literature Review, and Manuscript 3 reflects on the use of the research tool in Tukaley to improve the provision of latrines and handwashing facilities for children aged five to 12. Note that this is the same research project on which Manuscript 2 is based, with Manuscript 2 focusing on the results found.

Case Study Two considers the ethical challenges of conducting research with displaced children in humanitarian settings, using the Story Book methodology in refugee settlements in Adjumani District, Uganda; and Cox's Bazar refugee camps in Bangladesh. A full description of the development of the Story Book methodology (which was led by the author) has been provided in this Literature Review, and Manuscript 4 is an evaluation of the methodology.

Case Study One, on the operational challenges of conducting research in humanitarian settings with displaced children: The User-Centred Community Engagement methodology (Ethiopia)

In 2017, Elhra's Humanitarian Innovation Fund (HIF) launched an innovation challenge 'to create good practice guidance for rapid engagement with affected communities as end users to generate actionable and practical solutions for user-centred sanitation in emergencies … the guidance should be appropriate for the design of sanitation in the first stage (typically 12 weeks) of a rapid-onset emergency, but will be applicable to a range of humanitarian contexts, including protracted settings where rapid decision-making in sanitation design is necessary' (Sandison, 2017 p.9). Save the Children UK (STCUK) was one of the three humanitarian organisations chosen to implement community engagement approaches, and to do so it established a project partnership with Eclipse Experience (Eclipse), a human-centred research and design consultancy (together known as the Partners).

The Partners developed a methodology named User-Centred Community Engagement (UCCE) to improve the provision of latrines and handwashing facilities for children aged five to 12 in emergency settings. UCCE is composed of several components, the first being an Interactive Digital Survey (IDS) which is conducted using a tablet. Participants in the IDS are either children aged five to 12 (child respondents), or adults who care for children aged five to 12 (adult caregiver respondents). Note that an IDS was designed for each group of respondents.

By early 2019, the UCCE methodology had been successfully proved as a concept in Bangladesh and Iraq, and a further study was planned in Ethiopia. At this stage, the author worked with the Partners to amend the surveys used in Bangladesh and Iraq to explore the number of children aged 5 to 12 in an emergency setting wetting themselves, and demand for support to manage self-wetting in the home, in Tukaley, Ethiopia.

IDS version for adult caregiver respondents

The Data Collector must obtain verbal consent from the adult caregiver respondent before beginning the IDS. This is evidenced by the Data Collector selecting a tick box on the IDS. The respondent is then given the tablet to complete the IDS. Text (instructions, questions and answers) can be read by the respondent themselves, or can be read to the respondent by the Data Collector. The respondent first answers several questions about the latrine habits of the children aged five to 12 that they care for (read by the respondent or read aloud by the Data Collector). These questions have multiple choice answers (read by the respondent or read aloud by the Data Collector) and the respondents selects the appropriate answer by tapping the screen. The respondents are then guided through their latrine journey using interactive illustrations: instructions are provided (read by the respondent or read aloud by the Data Collector) to select “pain points” about the latrines by tapping on the illustrations (Figure 1) and follow-up questions with multiple choice answers (selected by tapping on the screen) are then asked about the reasons for their selection(s) (read by the respondent or read aloud by the Data Collector) (Figure 2). Each IDS takes around ten minutes and the answers given are anonymous.

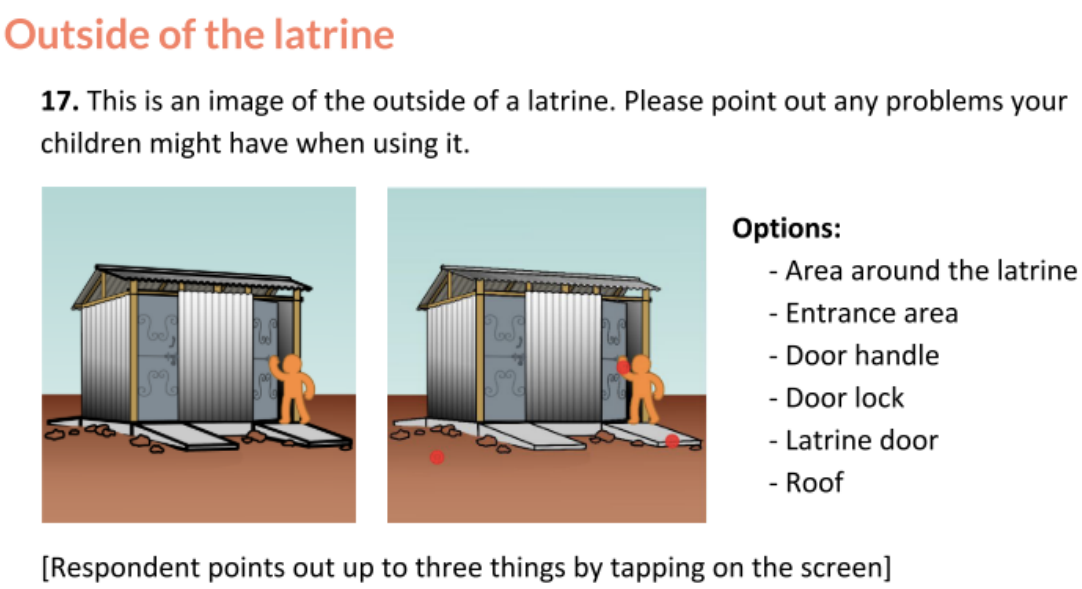


Figure 1 Example IDS question (adult caregiver and child surveys): respondents are asked to select 'pain points' about the latrines by tapping on illustrations (Eclipse Experience, 2019a)

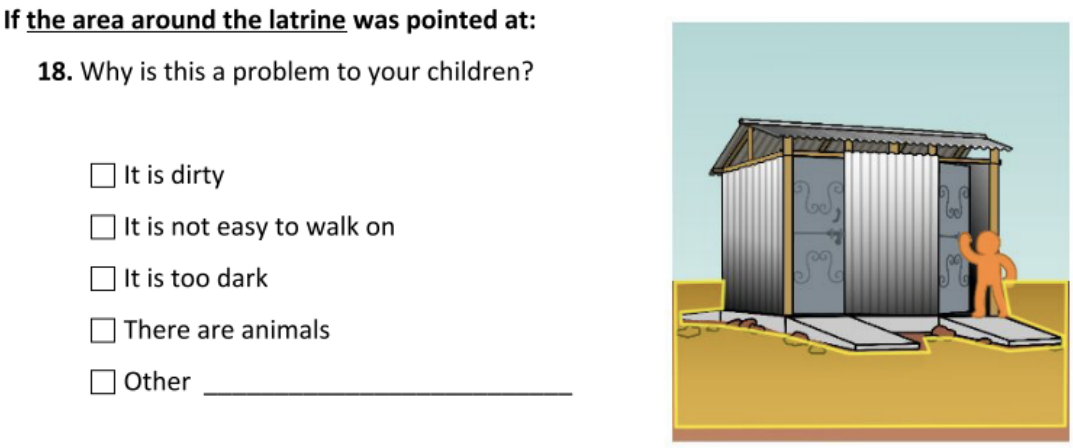


Figure 2 Example IDS question (adult caregiver and child surveys): respondents are asked questions with multiple choice answers (Eclipse Experience, 2019a)

IDS version for child respondents

For a child to be asked to take part in the IDS, their adult caregiver must first give consent for them to be asked. This is evidence by the Data Collector selecting a tick box on the adult caregiver IDS. If consent is provided, the Data Collector must then obtain verbal assent from the child respondent before beginning the IDS. This is evidenced by the Data Collector selecting a tick box on the child respondent's IDS. The respondent is then given the tablet to complete the IDS. Text (instructions, questions and answers) is read to the respondent by the Data Collector. The Data Collector first asks the child

respondent two questions about their latrine habits with answers given by tapping on illustrations (Figure 3).

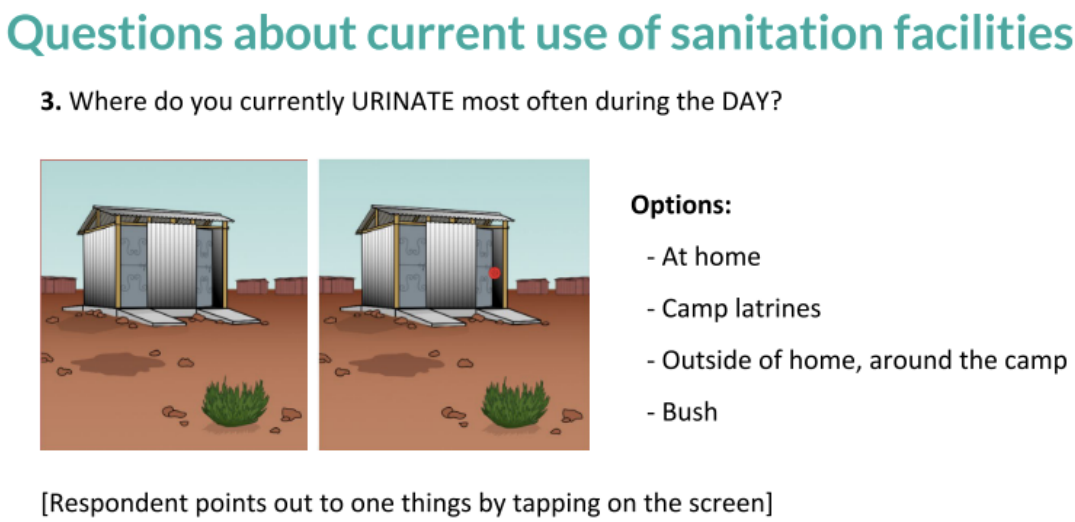


Figure 3 Example IDS question (child survey only): respondents are asked to provide answers by tapping on illustrations (Eclipse Experience, 2019b)

The Data Collector then asks questions about the sanitation facilities, with the respondents answering by tapping on the appropriate smiley face rating scale image (Figure 4).

Figure 4 Example IDS question (child survey only): respondents are asked to provide answers by tapping on the appropriate smiley face rating scale image (Eclipse Experience, 2019b)

The child respondents are then guided through their latrine journey using interactive illustrations: the Data Collector asks them to select “pain points” about the latrines by tapping on the illustrations (Figure 1) and then asks the child respondent follow-up questions with multiple choice answers (selected by tapping on the screen) about the reasons for their selection(s) (Figure 2). Each IDS takes around ten minutes and the answers given are anonymous.

Co-creation sessions

Once the first IDS has been conducted (IDS I), an automatically produced report is reviewed by engineers and the main “pain points” are identified. Co-creation sessions are then held with children and adult caregivers (separately) to explore the “pain points” and decide on design changes in a participatory way. The design changes that can be implemented are, and after a period of use a second IDS (IDS 2) is conducted in the same way as the first to collect feedback on the altered construction and identify whether there is a need for further alterations (Eclipse Experience, 2019c).

With successful proofs of concept completed in Bangladesh (December 2017, an early emergency context) and Iraq (February 2018, a protracted emergency context), Eclipse received a second grant from HIF to run a further pilot in Ethiopia with partners STCUK and Oxfam.

Please note that Manuscript 3 (Engaging with crisis-affected populations: An assessment of the User-Centred Community Engagement methodology as used in Tukaley, Ethiopia) is associated with this section of Part 3 of the Literature Review.

Case Study Two, on the ethical challenges of conducting research in humanitarian settings with displaced children: The Story Book methodology (Bangladesh and Uganda)

The 2019 HIF Innovation Challenge aimed to build “on existing evidence and insights to further understand the barriers to inclusion that people living with incontinence face, so that more holistic, effective and inclusive water, sanitation and hygiene (WASH) programmes can be developed” (Elrha, 2019). Funding was awarded to three partnerships, one of which consisted of lead organisations University of Leeds (United Kingdom) and The University of Western Australia; with partner organisations University of York (United Kingdom); Plan International UK, Plan International Uganda, Uganda Christian University, UNICEF Bangladesh and World Vision Bangladesh. The lead and partner organisations were supported by an Advisory Group (together known as the Research Team), which included specialists in conducting research with children, humanitarian affairs and incontinence. The Research Team was awarded funding to a) develop a methodology to engage children aged five to 11 in humanitarian contexts in

discussions of incontinence, so as to b) understand the barriers to inclusion and well-being that those living with incontinence, and their caregivers, face in Adjumani District, Uganda and Cox's Bazar, Bangladesh.

Using a rights-based approach, the starting-point from which to decide whether children should participate in any research project is that children have a right to be heard, even in a situation of crisis or its aftermath (United Nations, 1990; United Nations Committee on the Rights of the Child, 2009). From an initial stance of 'involving children in research is the right thing to do', researchers must decide if – *for their particular project* – it shouldn't be done because a) the matter being researched doesn't concern the child participants directly or indirectly; b) the researchers lack the capacity to either conduct the research or act on the findings; and/or c) the research could not be conducted ethically. When planning the research activities to be undertaken in Adjumani District and Cox's Bazar, the Research Team considered these questions in turn:

a) Is the research of relevance to the children?

The Research Team concluded that the subject matter of the research (that is, the experiences of children living with incontinence) was directly of concern to the proposed child participants, and that only they – and not an adult proxy – could genuinely voice their experiences (consideration of *EI 8: Relevance;* Table 4).

b) Does the Research Team have the capacity to conduct the research and act on the findings?

Of primary concern when involving children in research is to ensure that all necessary steps will be taken to safeguard the participants (Agar et al., 2005). This requires having researchers in the team with the minimum knowledge, skills and attitudes needed to facilitate and support meaningful participation with children (O'Kane, 2013 p.21). There is no shared standard for assessing a researcher's competencies and capacities; instead assessment is subjective and context-specific (Bennouna et al., 2017). Guidelines such as O'Kane's (2013 p.21) that provide ideal researcher specifications are therefore invaluable when recruiting those that will conduct the research. In Bangladesh the focus group facilitators were hygiene officers used to working with children. In Uganda the facilitators were research assistants from the Plan International Uganda database, known to have experience in qualitative data collection and who were familiar with the local community. The skills and experiences of the data collectors therefore met O'Kane's minimum requirements including knowledge of local context; facilitation skills; and having an attitude that valued children (2013 p.21). The participation of Plan

International UK, Plan International Uganda, UNICEF Bangladesh and World Vision Bangladesh was viewed as a demonstration of an organisational mandate to a) learn more about how to best support people living with incontinence in a humanitarian context, and b) to incorporate the findings into their existing WASH programmes (consideration of *EI 5: Institutional capacity to ethically involve children in research;* Table 4).

c) Can the research be conducted ethically?

As effective methodology and ethics go hand in hand, determining how the children would participate was crucial to deciding if the research could be conducted ethically (Thomas and O'Kane, 1998). In late-2019, UK-based members of the Research Team met to initially design the research tools to be used. Virtual workshops (rather than in-person due to Covid-19) were then held in July 2020 with Australia-, Uganda- and UK-based members of the Research Team to contextualise the research methodology and individual tools to be used in Adjumani District; and in December 2020, with Australia- and Bangladesh-based members of the Research Team to contextualise the research methodology and individual tools to be used in Cox's Bazar.

The research methodology was developed with the competencies and capacities of the proposed data collectors in mind. The day-to-day work of the proposed data collectors included focus group discussions (FGDs) and interviews with children aged five to 11, therefore the first decision point was whether to conduct FGDs or interviews. The Research Team's preference was to avoid conducting interviews with young children to avoid any repercussions should a participant be viewed as having been specifically selected to take part in a conversation about such a highly personal, sensitive and often stigmatised medical condition (UI). It was also felt that an interview on such a topic could be an intimidating process for a young child with little benefit for them.

In contrast, FGDs are "purposeful, facilitated discussions between a group of participants with similar characteristics" (Lansdown and O'Kane 2014 p.5). They generate data through interaction amongst the participants; and compared to an interview responses are deeper and more considered as participants have the opportunity to listen to others, reflect and consider their own viewpoint, and there is more scope for the natural emergence of issues (Finch and Lewis, 2003). This is of course all reliant on the culture of the participants encouraging free expression and the Bangladesh- and Uganda-based members of the Research Team provided assurance that children in Cox's Bazar and

Adjumani District were able to express themselves in the context of a FGD without fear of punishment (Bennouna et al., 2017).

Agar et al. (2011) found that FGDs work well with children, and they have also been shown to be an ideal qualitative research method when discussing sensitive topics with children: the group context can provide mutual support for shy children, articulate children can model for those lacking in confidence, and the peer support helps to redress the power imbalance that exists between adult and child during an interview (Jones, 2008; Lansdown and O'Kane, 2014). However, researchers need to balance the benefits of FGDs with the risks that a) disclosures may be shared outside of the group, and b) that discussion may stress or distress participants (Agar et al., 2005). Verbal introductions to FGDs must therefore outline that although the children can discuss the FGD with non-participants, details including who said what should not be shared, however there is a risk that they may be (Agar et al., 2005). The FGD facilitator must also emphasise that participation is voluntary, and anyone can leave at any time for any reason including if they do not want to speak or hear what is being said. Having a second person present to observe can also support the facilitator to recognise signs of stress or distress in participants, and take the appropriate action (Feinstein et al., 2004). The Research Team therefore concluded that conducting FGDs would be appropriate (consideration of *EI 1: Harms and benefits; and EI 6 Understanding power relations;* Table 4).

The size and composition of a focus group is critical in shaping the group dynamic (Finch and Lewis, 2003). Members of the Advisory Team guided that FGDs with children should have up to six participants, which is in-line with the literature: Finch and Lewis (2003) found that children are likely to feel more comfortable in a smaller group. Given the personal and sensitive nature of the issues being discussed, it was felt that groups should be split by gender, and it was also decided that groups should be split by age. This was partly due to the knowledge that the global prevalence of UI follows a trend of decline by age and therefore different age groups may have different experiences of the condition; but also following guidance from the Bangladesh Research Team who felt that children aged eight or more were noticeably more mature. The split was decided as five to seven-years old and eight to 11 years old. Further, the Bangladesh Research Team advised that the facilitator of the FGD should be of the same gender as the participants, particularly for the older ages (eight to 11) as otherwise they may be too embarrassed to contribute (consideration of *EI 1: Harms and benefits;* Table 4).

The research methods used during FGDs should reflect the capacities of the participants and ideally provide an opportunity for recreation and self-expression, particularly in a humanitarian context where such opportunities could be rare and therefore even more valuable (Berman et al., 2016). The use of drawing methods in research with children is known to be very successful as they can minimise the power relationship between adult researchers and the children; give participants time to think about what they want to communicate; help discussions about more complicated, sensitive and abstract issues; uncover subconscious perspectives; provide learning opportunities; and be fun and relaxing (Thomas and O'Kane, 1998; Eldén, 2013; Literat, 2013). Indeed in Cox's Bazar members of the Bangladesh Research Team were already adapting methods used by Clowns Without Borders to educate the children on topics such as hand-washing. These methods included singing songs, playing games, telling stories, and drawing pictures.

The Research Team therefore designed a collaborative 'Story Book methodology', whereby the children collectively drew on sheets ('Drawing Sheets' with outline images provided) to create a story about an imaginary child living in Adjumani District or Cox's Bazar who sometimes wet themselves. The group explored the feelings of the imaginary child at different times during the day (for example, when playing with friends) and including when they wet themselves, and the feelings of the imaginary child's caregiver after an episode of self-wetting. The group also explored a time period, for example a morning, in the life of the imaginary child to understand the wider impacts of an episode of self-wetting and to ask the children for suggestions as to how to mitigate such impacts. Note that the use of an *imaginary child* rather than asking participants to share personal experiences of incontinence reduced the risk of a) a child becoming distressed at being asked to share such experiences and b) a participant being identified by friends, family and the wider community as experiencing incontinence which may result in negative consequences due to the stigma associated with the condition. This 'imaginary' approach was particularly favoured by the Bangladesh Research Team as some members knew of children that had participated in FGDs on menstrual hygiene management and who were later teased by fellow participants (consideration of *EI 1: Harms and benefits;* Table 4).

With regards to *EI 4: Compensation and payment (*Table 4), given the age of the participants the Research Team agreed that the provision of compensation should be limited to the food and drinks provided during the FGD. And finally, Schenk and Williamson (2005) advise that methods and tools used in FGDs should be "informed by discussions with the children themselves and with adult community members" (p.20), and so the tools were modified after each FGD, informed by the children themselves.

For example, after the first pilot FGD additional breaks were added to the FGD to ensure that the attention of the children was kept.

Note that consideration of *EI 2: Informed consent and capacities of individuals* and *EI 3: Privacy and confidentiality (*Table 4) are detailed in the Methods section of the following manuscript (Manuscript 4); where details of *EI 7: Communication of results (*Table 4) are also provided.

Please note that Manuscript 4 (Understanding children's experiences of self-wetting in humanitarian contexts: An evaluation of the Story Book methodology) is associated with this section of Part 3 of the Literature Review.

References (Literature Review)

Abrams, P., Cardozo, L., Wagg, A. and Wein, A. (eds.). 2017. Incontinence 6th Edition [Online]. Bristol, UK: ICI-ICS. International Continence Society. [Accessed 9 November 2021]. Available from: https://www.ics.org/education/icspublications/icibooks/6thicibook.

Agar, M., Macdonald, J., Basch, C.E., Bertrand, J.T., Brown, J.E., Ward, V.M., Bogardus, E.S., Charlesworth, L.W., Rodwell, M.K., Clark, C.D., Clark, L., Marsh, G.W., Davis, M., Igoe, J., Stember, M., Doswell, W.M., Vandestienne, G., Elliott, R., Fischer, C.T., Rennie, D.L., Garley, D., Gallop, R., Johnston, N., Pipitone, J., Greenbaum, T.L., Heary, C., Hennessy, E., Hill, M., Laybourn, A., Borland, M., Houghton, S., Durkin, K., Carroll, A., Hunter, A.J., Chandler, G.E., Kidd, P., Townley, K., Cole, H., Mcknight, R., Piercy, L., Kisker, E.E., Klein, J.D., Forehand, B., Oliveri, J., Patterson, C.J., Kupersmidt, J.B., Strecher, V., Krueger, R.A., Levine, I.S., Zimmerman, J.D., Lewis, A., Maccoby, E.E., Macmullin, C., Odeh, J., Mauthner, M., Mayall, B., Mcdonald, W.J., Topper, G.E., Mcmahon, M., Patton, W., Merrick, E., Merton, R.K., Kendall, P.L., Morgan, D.L., Morningstar, M.E., Turnbull, A.P., Turnbull, H.R., Rinne, M.G., Smith, M.W., Spethmann, B., Stanton, B.F., Aronson, R., Borgatti, S., Galbraith, J., Feigelman, S., Turner, S., Vaughn, S., Schumm, J.S., Sinagub, J., Wight, D., Greene, S. and Hogan, D. 2005. Exploring Children's Views through Focus Groups In: S. Greene and D. Hogan, eds. Researching Children's Experience [Online]. Sage. [Accessed 19 January 2022]. Available from: https://dx.doi.org/10.4135/9781849209823.

Akinyanju, O., Agbato, O., Oluwole Ogunmekan, A. and Okoye, J.U. 1989. Enuresis in Sickle Cell Disease. I. Prevalence Studies. Journal of Tropical Pediatrics. 35, pp.24–26.

American Psychiatric Association 2013. Diagnostic and statistical manual of mental disorders (DSM-5) 5th ed. Washington DC, United States: American Psychiatric Publishing.

Anderson, B., Thimmesch, I., Aardsma, N., Ed D, M.T., Carstater, S. and Schober, J. 2014. The prevalence of abnormal genital findings, vulvovaginitis, enuresis and encopresis in children who present with allegations of sexual abuse. Journal of Pediatric Urology. 10(6), pp.1216–1221.

Austin, P.F., Bauer, S.B., Bower, W., Chase, J., Fanco, I., Hoebeke, P., Rittig, S., Walle, J. Vande, von Guntard, A., Wright, A., Yang, S.S. and Nevéus, T. 2016. The Standardization of Terminology of Lower Urinary Tract Function in Children and Adolescents: Update Report From the Standardization Committee of the International Children's Continence Society. Neurourology and Urodynamics. 35, pp.471–481.

Bachmann, C.J., Heilenkötter, K., Janhsen, E., Ackmann, C., Thomä, M., Lax, H. and Bachmann, H. 2008. Long-term effects of a urotherapy training program in children with functional urinary incontinence: A 2-year follow-up. Scandinavian Journal of Urology and Nephrology. 42(4), pp.337–343.

Behnke, N., Cronk, R., Snel, M., Moffa, M., Tu, R., Banner, B., Folz, C., Anderson, D., Macintyre, A., Stowe, E. and Bartram, J. 2018. Improving environmental conditions for involuntarily displaced populations: water, sanitation, and hygiene in orphanages, prisons, and refugee and IDP settlements. Journal of Water Sanitation and Hygiene for Development. (October), pp.1–7.

Bennouna, C., Mansourian, H. and Stark, L. 2017. Ethical considerations for children's participation in data collection activities during humanitarian emergencies: A Delphi review. Conflict and Health. 11(5).

Berman, G., Hart, J., O'Mathúna, D., Mattellone, E., Potts, A., O'Kane, C., Shusterman, J. and Tanner, T. 2016. What We Know about Ethical Research Involving Children in Humanitarian Settings An overview of principles, the literature and case studies, Innocenti Working Paper No. 2016-18 [Online]. Florence, Italy. [Accessed 11 January 2022]. Available from: https://www.unicef-irc.org/publications/849-what-we-know-about-ethical-research-involving-children-in-humanitarian-settings-an.html.

Bower, W.F., Moore, K.H., Shepherd, R.B. and Adams, R.D. 1996. The epidemiology of childhood enuresis in Australia. British Journal of Urology. 78(4), pp.602–606.

Buckley, B.S. and Lapitan, M.C.M. 2010. Prevalence of Urinary Incontinence in Men, Women, and Children - Current Evidence: Findings of the Fourth International Consultation on Incontinence. Urology. 76(2), pp.265–270.

Buckley, B.S., Sanders, C.D., Spineli, L., Deng, Q. and Kwong, J.S.W. 2019. Conservative interventions for treating functional daytime urinary incontinence in children.

Butler, R. and Heron, J. 2007. An exploration of children's views of bed-wetting at 9 years. Child Care Health Dev. 34(1), pp.65–70.

Butler, R.J., Golding, J. and Northstone, K. 2005. Nocturnal enuresis at 7.5 years old: Prevalence and analysis of clinical signs. BJU International. 96(3), pp.404–410.

Can, G., Topbas, M., Okten, A. and Kizil, M. 2004. Child abuse as a result of enuresis. Paediatrics International. 46, pp.64–66.

Chang, S.-J., Van Laecke, E., Bauer, S.B., Von Gontard, A., Bagli, D., Bower, W.F., Renson, C., Kawauchi, A. and Shei-Dei Yang, S. 2017. Treatment of daytime urinary incontinence: a standardisation document from the International Children's Continence Society. Neurology and Urodynamics. 36, pp.43–50.

Chao, S.M., Yap, H.K., Tan, A., Ong, E.K., Murugasu, B., Low, E.H. and Tan, S.P. 1997. Primary monosymptomatic nocturnal enuresis in Singapore - Parental perspectives in an Asian community. Annals of the Academy of Medicine, Singapore. 26(2), pp.179–83.

CP MERG 2012. Ethical principles, dilemmas and risks in collecting data on violence against children: A review of available literature [Online]. New York, United States. Available from: https://resourcecentre.savethechildren.net/document/ethical-principles-dilemmas-and-risks-collecting-data-violence-against-children-review/.

Crowle, A. and Harley, C. 2020. Development of a biotensegrity focused therapy for the treatment of pelvic organ prolapse: A retrospective case series. Journal of Bodywork and Movement Therapies. 24(1), pp.115–125.

Curtis, P., Thompson, J. and Fairbrother, H. 2018. Migrant children within Europe: a systematic review of children's perspectives on their health experiences. Public Health. 158, pp.71–85.

Dahab, M. 2017. Operational challenges of implementing health research in humanitarian settings. Lessons learned from R2HC funded studies. [Online]. Cardiff: Elrha. Available from: https://www.elrha.org/researchdatabase/operational-challenges-implementing-health-research-humanitarian-settings/.

Deshpande, A. V., Craig, J.C., Smith, G.H.H. and Caldwell, P.H.Y. 2012. Management of daytime urinary incontinence and lower urinary tract symptoms in children. Journal of Paediatrics and Child Health. 48(2), pp.E44–E52.

Dossche, L., Vande Walle, J. and Van Herzeele, C. 2016. The pathophysiology of monosymptomatic nocturnal enuresis with special emphasis on the circadian rhythm of renal physiology. European Journal of Pediatrics. 175, pp.747–754.

Eclipse Experience 2019a. UCCE Caregiver Interactive Digital Survey (Ethiopia pilot). [Accessed 16 November 2021]. Available from: http://www.eclipse-experience.com/user-centred-community-engagement/downloads.

Eclipse Experience 2019b. UCCE Children Interactive Digital Survey (Ethiopia pilot). [Accessed 16 November 2021]. Available from: http://www.eclipse-experience.com/user-centred-community-engagement/downloads.

Eclipse Experience 2019c. User-Centred Community Engagement. [Accessed 16 November 2021]. Available from: http://www.eclipse-experience.com/user-centred-community-engagement.

Eldén, S. 2013. Inviting the messy: Drawing methods and 'children's voices'. Childhood. 20(1), pp.66–81.

Elrha 2019. WASH Innovation Challenge: Exploring the barriers to inclusion faced by people living with incontinence. [Accessed 14 January 2022]. Available from:

https://www.elrha.org/funding-opportunity/wash-innovation-challenge-barriers-to-inclusion-faced-by-people-living-with-incontinence/.

Esezobor, C.I., Akintan, P., Nwaogazie, U., Akinwunmi, E., Temiye, E., Akinsulie, A. and Gbadegesin, R. 2018. Enuresis in children and adolescents with sickle cell anaemia is more frequent and substantially different from the general population. PLoS ONE. 13(8), pp.1–12.

Esezobor, C.I., Balogun, M.R. and Ladapo, T.A. 2015. Prevalence and predictors of childhood enuresis in southwest Nigeria: Findings from a cross-sectional population study. Journal of Pediatric Urology. 11, pp.1–6.

EU Science Hub 2020. Humanitarian crises around the world are becoming longer and more complex. [Accessed 5 November 2021]. Available from: https://ec.europa.eu/jrc/en/news/humanitarian-crises-around-world-are-becoming-longer-and-more-complex.

Farrington, M. 2019. Conversation with Claire Rosato-Scott 20 February 2019.

Feinstein, C., Fyrk, K., Gezelius, H., Heiberg, T., Jareg, E., Karkara, R., Modig, C., Nilsson, M., Sheth, A. and Stevenson, S. 2004. So You Want to Involve Children in Research? [Online]. [Accessed 19 January 2022]. Available from: https://www.savethechildren.org.uk/content/dam/global/reports/education-and-child-protection/so-you-want-to-involve-children-in-research.pdf.

Feng, W.C. and Churchill, B.M. 2001. Dysfunctional elimination syndrome in children without obvious spinal cord diseases. Pediatric Clinics of North America. 48(6), pp.1489–1504.

Ferrara, P., Di Giuseppe, M., Fabrizio, G.C., Sbordone, A., Amato, M., Cutrona, C. and Verrotti, A. 2016. Enuresis and Punishment: The Adverse Effects on Child Development and on Treatment. Urologia Internationalis. 97(4), pp.410–415.

Ferron, S. and Lloyd, A. 2014. Emergency WASH for children [Online]. Available from: http://www.elrha.org/wp-content/uploads/2015/02/2014-10-11-Emergency-WASH-for-Children-Final.pdf.

Finch, H. and Lewis, J. 2003. Focus Groups In: J. Ritchie and J. Lewis, eds. Qualitative Research Practice - A Guide for Social Science Students and Researchers. Sage, pp.170–198.

Fockema, M.W., Candy, G.P., Kruger, D. and Haffejee, M. 2012. Enuresis in South African children: Prevalence, associated factors and parental perception of treatment. BJU International. 110, pp.1114–1120.

Franco, I., Von Gontard, A. and De Gennaro, M. 2013. Evaluation and treatment of nonmonosymptomatic nocturnal enuresis: A standardization document from the International Children's Continence Society. Journal of Pediatric Urology. 9(2), pp.234–243.

Garcia, J.A., Crocker, J. and Wyman, J.F. 2005. Breaking the Cycle of Stigmatization. Managing the stigma of incontinence in social interactions. Journal of Wound, Ostomy and Continence Nursing. 32(January/February), pp.38–52.

Gensch, R., Jennings, A., Renggli, S. and Reymond, P. 2018. Compendium of Sanitation Technologies in Emergencies [Online]. Berlin, Germany. [Accessed 5 November 2021]. Available from: https://www.emersan-compendium.org/en/.

Graham, A., Powell, M., Taylor, N., Anderson, D. and Fitzgerald, R. 2013. Ethical Research Involving Children [Online]. Florence, Italy. [Accessed 11 January 2022]. Available from: https://www.unicef-irc.org/publications/pdf/eric-compendium-approved-digital-web.pdf.

Great Ormond Street Hospital 2017. Urinary incontinence. [Accessed 23 November 2021]. Available from: https://www.gosh.nhs.uk/conditions-and-treatments/conditions-we-treat/urinary-incontinence.

Grzeda, M.T., Heron, J., Von Gontard, A. and Joinson, C. 2017. 177. Effects of urinary incontinence on psychosocial outcomes in adolescence. European Child & Adolescent Psychiatry. 26, pp.649–658.

Hagstroem, S., Rittig, S., Kamperis, K. and Djurhuus, J.C. 2010. Timer Watch Assisted Urotherapy in Children: A Randomized Controlled Trial. The Journal of Urology. 184(4), pp.1482–1488.

Hirani, S.A.A. and Richter, S. 2019. Maternal and Child Health During Forced Displacement. Journal of Nursing Scholarship. 0(0), pp.1–10.

Hjälmås, K. 1992. Functional daytime incontinence: definitions and epidemiology. Scandinavian Journal of Urology and Nephrology. Supplementum. 141, pp.39–44.

Järvelin, M.R., Moilanen, I., Vikeväinen-Tervonen, L. and Huttunen, N. 1990. Life Changes and Protective Capacities in Enuretic and Non-Enuretic Children. Journal of Child Psychology and Psychiatry. 31(5), pp.763–774.

Joinson, C., Heron, J., Emond, A. and Butler, R. 2007. Psychological Problems in Children with Bedwetting and Combined (day and night) Wetting: A UK Population-Based Study. Journal of Pediatric Psychology. 25(5), pp.605–616.

Joinson, C., Sullivan, S., Von Gontard, A. and Heron, J. 2016. Stressful Events in Early Childhood and Developmental Trajectories of Bedwetting at School Age. Journal of Pediatric Psychology. 41(9), pp.1002–1010.

Jones, L. 2008. Responding to the needs of children in crisis. International Review of Psychiatry. 20(3), pp.291–303.

Jones, L., Rrustemi, A., Shahini, M. and Uka, A. 2003. Mental health services for war-affected children. British Journal of Psychiatry. 183, pp.540–546.

Jurković, M., Tomašković, I., Tomašković, M., Zore, B.S., Pavić, I. and Roić, A.C. 2019. Refugee status as a possible risk factor for childhood enuresis. International Journal of Environmental Research and Public Health. 16(7).

Kajiwara, M., Inoue, K., Usui, A., Kurihara, M. and Usui, T. 2004. The micturition habits and prevalence of daytime urinary incontinence in Japanese primary school children. Journal of Urology. 171(1), pp.403–407.

Kanaheswari, Y. 2003. Epidemiology of childhood nocturnal enuresis in Malaysia. Journal of Paediatrics and Child Health. 39, pp.118–123.

Keith, R. Mac 1968. A Frequent Factor in the Origins of Primary Nocturnal Enuresis: Anxiety in the Third Year of Life. Developmental Medicine and Child Neurology. 10(4), pp.465–470.

Koff, S.A., Wagner, T.T. and Jayanthi, V.R. 1998. The relationship among dysfunctional elimination syndromes, primary vesicoureteral reflux and urinary tract infections in children. The Journal of Urology. 160(3 Part 2), pp.1019–1022.

Kohrt, B.A., Mistry, A.S., Anand, N., Beecroft, B. and Nuwayhid, I. 2019. Health research in humanitarian crises: An urgent global imperative. BMJ Global Health. 4(6), pp.1–8.

Lansdown, G. and O'Kane, C. 2014. A toolkit for monitoring and evaluating children's participation. Booklet 3 [Online]. [Accessed 18 October 2019]. Available from: https://resourcecentre.savethechildren.net/node/8080/pdf/me_toolkit_booklet_3_low_res1.pdf.

Lee, S.D., Sohn, D.W., Lee, J.Z., Park, N.C. and Chung, M.K. 2000. An epidemiological study of enuresis in Korean children. BJU International. 85(7), pp.869–873.

Leresche, E., Truppa, C., Martin, C., Marnicio, A., Rossi, R., Zmeter, C., Harb, H., Hamadeh, R.S. and Leaning, J. 2020. Conducting operational research in humanitarian settings: Is there a shared path for humanitarians, national public health authorities and academics? Conflict and Health. 14(1), pp.1–14.

Lind, D. 2018. 'A recipe for toxic stress': an expert on why Trump's family separation policy is so damaging to kids. Vox. [Online]. [Accessed 9 November 2021]. Available from: https://www.vox.com/policy-and-politics/2018/6/20/17480680/child-separate-parent-trauma-effects.

Literat, I. 2013. 'A pencil for your thoughts': Participatory drawing as a visual research method with children and youth. The International Journal of Qualitative Methods. February.

Loening-Baucke, V. 2007. Prevalence rates for constipation and faecal and urinary incontinence. Archives of Disease in Children. 92, pp.486–489.

Makrani, A.H., Moosazadeh, M., Nasehi, M.M., Abedi, G., Afshari, M., Farshidi, F. and Aghaei, S. 2015. Prevalence of Enuresis and its Related Factors among Children in Iran: A Systematic Review and Meta-analysis. International Journal of Pediatrics. 3(6), pp.995–1004.

Mathew, J.L. 2010. Evidence-Based Management of Nocturnal Enuresis: An Overview of Systematic Reviews. Indian Pediatrics. 47, pp.777–780.

Mattsson, S. 1994. Urinary incontinence and nocturia in healthy schoolchildren. Acta Paediatrica. 83(9), pp.950–954.

Mistry, A.S., Kohrt, B.A., Beecroft, B., Anand, N. and Nuwayhid, I. 2021. Introduction to collection: confronting the challenges of health research in humanitarian crises. Conflict and Health. 15(1), pp.1–6.

Moher, D., Liberati, A., Tetzlaff, J., Altman, D.G. and The PRISMA Group 2009. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. PLoS Medicine. 6(7), p.e1000097.

Morison, M., Staines, H. and Gordon, A. 2004. A systematic review of the prevalence of nocturnal enuresis In: ICS/IUGA [Online]. Paris, France. [Accessed 9 November 2021]. Available from: https://www.ics.org/Abstracts/Publish/42/000093.pdf.

Morison, M.J. 1998. Parents' and young people's attitudes towards bedwetting and their influence on behaviour, including readiness to engage in and persist with treatment. British Journal of Urology. 81(Suppl. 3), pp.56–66.

Mota, D.M. and Barros, A.J.D. 2008. Toilet training: methods, parental expectations and associated dysfunctions. Jornal de Pediatria. 84(1), pp.9–17.

Nevéus, T. 2011. Nocturnal enuresis - theoretic background and practical guidelines. Pediatric Nephrology. 26(8), pp.1207–1214.

O'Kane, C. 2013a. Review of children's participation in humanitarian programming [Online]. London, United Kingdom. [Accessed 11 January 2022]. Available from: https://resourcecentre.savethechildren.net/document/review-childrens-participation-humanitarian-programming/.

O'Kane, C. 2013b. Guidelines for Children's Participation in humanitarian programming [Online]. [Accessed 11 January 2022]. Available from: https://resourcecentre.savethechildren.net/document/guidelines-childrens-participation-humanitarian-programming/.

OCHA 2021. Global Humanitarian Overview 2022 [Online]. Istanbul, Turkey. Available from: https://reliefweb.int/sites/reliefweb.int/files/resources/Global Humanitarian Overview 2022.pdf.

Oxfam 2013. Oxfam Minimum Requirements for WASH Programmes (MR-WASH) [Online]. Oxfam, United Kingdom. [Accessed 5 November 2021]. Available from:

https://policy-practice.oxfam.org.uk/publications/oxfam-minimum-requirements-for-wash-programmes-mr-wash-300134.

Piyasil, V. and Udomsup, J. 2002. Enuresis in children 5-15 years at Queen Sirikit National Institute of Child Health. Journal of the Medical Association of Thailand. 85(1), pp.11–6.

REACH Initiative 2018. Water, Sanitation and Hygiene Follow-up Assessment Monsoon Season (August-October 2018) [Online]. [Accessed 19 November 2021]. Available from: https://reliefweb.int/report/bangladesh/water-sanitation-and-hygiene-follow-assessment-monsoon-season-august-october-19.

Rosato-Scott, C., Alam, M., Evans, B.E., Rose, J., Wozei, E. and Barrington, D.J. tbc. Understanding children's experiences of self-wetting in humanitarian contexts: An evaluation of the Story Book methodology (Submitted). PLOS Global Public Health.

Rosato-Scott, C., Barrington, D.J., Bhakta, A.N., House, S., Mactaggart, I. and Wilbur, J. 2020. Incontinence: We Need to Talk About Leaks [Online]. Brighton: IDS. Available from: https://doi.10.19088/SLH.2020.005.

Rosato-Scott, C., Evans, B.E. and Barrington, D.J. 2021a. CHILD-SAN: a new disability-inclusive framework for emergency sanitation for children aged five to 11, based on a systematic review of existing guidance. Journal of International Humanitarian Action. 6(1).

Rosato-Scott, C. and Barrington, D.J. tbc. Engaging with crisis-affected populations: An assessment of the User-Centred Community Engagement methodology as used in Tukaley, Ethiopia. Journal of Humanitarian Affairs. tbc.

Rosato-Scott, C.A. and Barrington, D.J. 2018. Incontinence in Zambia: initial investigation into the coping strategies of sufferers and carers. Waterlines. 37(3), pp.190–206.

Rosato-Scott, C.A., Evans, B.E., Varampath, A., Fehnert, B. and Barrington, D.J. 2021b. Urinary incontinence in children aged 5 to 12 in an emergency setting: lessons learned in Ethiopia. Waterlines. 40(3), pp.179–191.

Rosato-Scott, C.A., Giles-Hansen, C., House, S., Wilbur, J., Macauley, M., Barrington, D.J., Culmer, P. and Burke, L. 2019. Guidance on supporting people with incontinence in humanitarian and low- and middle-income contexts (LMICs).

Ruiz-Casares, M., Collins, T.M., Tisdall, E.K.M. and Grover, S. 2016. Children's rights to participation and protection in international development and humanitarian interventions: nurturing a dialogue. The International Journal of Human Rights. 21(1), pp.1–13.

Ryan, F. 2018. 'It's horrifically painful': the disabled women forced into unnecessary surgery. The Guardian. [Online]. [Accessed 21 November 2021]. Available from:

https://www.theguardian.com/society/2018/aug/06/disabled-women-surgery-catheter-accessible-toilets.

Sandison, P. 2017. We're Listening: An evaluation of user-centred community engagement in emergency sanitation [Online]. [Accessed 16 November 2021]. Available from: https://oxfamilibrary.openrepository.com/bitstream/handle/10546/620617/gd-listening-community-engagement-emergency-sanitation-050219-en.pdf?sequence=1&isAllowed=y.

Sapi, M.C., Vasconcelos, J.S.P., Silva, F.G., Damião, R. and Da Silva, E.A. 2009. Assessment of domestic violence against children and adolescents with enuresis. Jornal de Pediatria. 85(5), pp.433–437.

Save the Children 2016. Childhood under siege. Living and dying in besieged areas of Syria [Online]. London, United Kingdom. [Accessed 9 November 2021]. Available from: https://resourcecentre.savethechildren.net/document/childhood-under-siege-living-and-dying-besieged-areas-syria/.

Schaeffer, A.J. and Diamond, D.A. 2014. Pediatric urinary incontinence: Classification, evaluation, and management. African Journal of Urology. 20, pp.1–13.

Schenk, K. and Williamson, J. 2005. Ethical Approaches to Gathering Information from Children and Adolescents in International Settings: Guidelines and Resources [Online]. [Accessed 19 January 2022]. Available from: https://www.popcouncil.org/uploads/pdfs/horizons/childrenethics.pdf.

Schleip, R. 2019. Emotional link to fascial tension. [Accessed 9 November 2021]. Available from: https://www.fasciaresearch.de/faq#paragraph4.

Schlomer, B., Rodriguez, E., Weiss, D. and Copp, H. 2013. Parental beliefs about nocturnal enuresis causes, treatments, and the need to seek professional medical care. Journal of Pediatric Urology. 9, pp.1043–1048.

Schober, J.M., Lipman, R., Haltigan, J.D. and Kuhn, P.J. 2004. The impact of monosymptomatic nocturnal enuresis on attachment parameters. Scandinavian Journal of Urology and Nephrology. 38(1), pp.47–52.

Shahabuddin, A.S.M., Sharkey, A.B., Jackson, D., Rutter, P., Hasman, A. and Sarker, M. 2020. Carrying out embedded implementation research in humanitarian settings: A qualitative study in Cox's Bazar, Bangladesh. PLoS Medicine. 17(7), pp.1–13.

Shaylor, E. 2021. Email exchange with Claire Rosato-Scott, 22 November 2021.

Shaylor, E. 2022. Email exchange with Claire Rosato-Scott 1 April 2022.

Shortall, C.K., Glazik, R., Sornum, A. and Pritchard, C. 2017. On the ferries: the unmet health care needs of transiting refugees in Greece. International Health. 9, pp.272–280.

Söderstrom, U., Hoelcke, M., Alenius, L., Söderling, A.C. and Hjern, A. 2004. Urinary and faecal incontinence: A population-based study. Acta Paediatrica. 93(3), pp.386–389.

Spencer, G., Smith, M., Thompson, J., Fairbrother, H., Hoare, K., Fouché, C. and Curtis, P. 2019. Health experiences of children and young people who migrate-Opportunities for health education. Health Education Journal. 78(1), pp.96–107.

Sphere Association 2018. The Sphere Handbook: Humanitarian Charter and Minimum Standards in Humanitarian Response [Online] 4th ed. Geneva, Switzerland: Sphere Association. [Accessed 5 November 2021]. Available from: https://spherestandards.org/handbook-2018/.

Sureshkumar, P., Bower, W., Craig, J.C. and Knight, J.F. 2003. Treatment of daytime urinary incontinence in children: A systematic review of randomized controlled trials. Journal of Urology. 170(1), pp.196–200.

Sureshkumar, P., Craig, J.C., Roy, L.P. and Knight, J.F. 2000. Daytime urinary incontinence in primary school children: A population-based survey. The Journal of Pediatrics. 137(6), pp.814–818.

Tanner, S. and O'Connor, M. 2017. A safe place to shine. Creating opportunities and raising voices of adolescent girls in humanitarian settings [Online]. The Hague, The Netherlands. [Accessed 5 November 2021]. Available from: https://www.rescue.org/sites/default/files/document/2248/irccompassglobalreport.pdf.

The Alliance for Child Protection in Humanitarian Action 2019. Minimum Standards for Child Protection in Humanitarian Action, 2019 Edition.

Theunis, M., Van Hoecke, E., Paesbrugge, S., Hoebeke, P. and Vande Walle, J. 2002. Self-image and performance in children with nocturnal enuresis. European Urology. 41(6), pp.660–667.

Thomas, N.P. and O'Kane, C. 1998. The ethics of participatory research with children. Children & Society. 12, pp.336–348.

UNHCR 2021. Refugee Data Finder. [Accessed 5 November 2021]. Available from: https://www.unhcr.org/refugee-statistics/download/?url=E1ZxP4.

UNICEF 2010. Core Commitments for Children in Humanitarian Action [Online]. New York, United States: UNICEF. [Accessed 5 November 2021]. Available from: https://www.unicef.org/media/59736/file/Core-commitments-for-children.pdf.

UNICEF 2012. Water, Sanitation and Hygiene (WASH) in Schools [Online]. New York, United States. Available from: https://www.unicef.org/publications/files/CFS_WASH_E_web.pdf.

UNICEF 2015. UNICEF Procedure for Ethical Standards in Research, Evaluation, Data Collection and Analysis [Online]. [Accessed 11 January 2022]. Available from: https://www.unicef.org/media/54796/file.

UNICEF 2016. Uprooted. The growing crisis for refugee and migrant children [Online]. New York, United States. [Accessed 5 November 2021]. Available from: https://www.unicef.org/reports/uprooted-growing-crisis-refugee-and-migrant-children.

UNICEF 2021. UNICEF Humanitarian Action for Children [Online]. Available from: https://www.unicef.org/media/112536/file/HAC-2022-Overview.pdf.

United Nations 1990. The United Nations Convention on the Rights of the Child [Online]. New York, United States. [Accessed 3 November 2021]. Available from: https://www.unicef.org.uk/what-we-do/un-convention-child-rights/.

United Nations 2015. Resolution adopted by the General Assembly on 17 December 2015. 70/169. The human rights to safe drinking water and sanitation. [Accessed 23 September 2023]. Available from: https://undocs.org/en/A/RES/70/169.

United Nations 2016. Sustainable Development Goal 6. [Accessed 5 November 2021]. Available from: https://sustainabledevelopment.un.org/sdg6.

United Nations Committee on the Rights of the Child 2009. General Comment No.12. on the Right of the Child to be Heard [Online]. Geneva, Switzerland. Available from: https://www.refworld.org/docid/4ae562c52.html.

Veneme, V. 2015. The unlikely sanitary pad missionary. [Accessed 9 November 2021]. Available from: https://www.bbc.co.uk/news/magazine-34925238.

Van Aggelpoel, T., der Cruyssen, V.K., Wachter, D.S. and Clippele, D. V 2017. Intercultural differences in toilet training In: ICS 2017 [Online]. Florence, Italy. [Accessed 9 November 2021]. Available from: https://www.ics.org/2017/abstract/815.

WHO 2006. Constitution of the World Health Organisation [Online]. Geneva, Switzerland. [Accessed 5 November 2021]. Available from: https://www.who.int/governance/eb/who_constitution_en.pdf.

WHO 2008. Managing WHO Humanitarian Response in the Field [Online]. Geneva, Switzerland. [Accessed 5 November 2021]. Available from: https://www.who.int/publications-detail-redirect/managing-who-humanitarian-response-in-the-field.

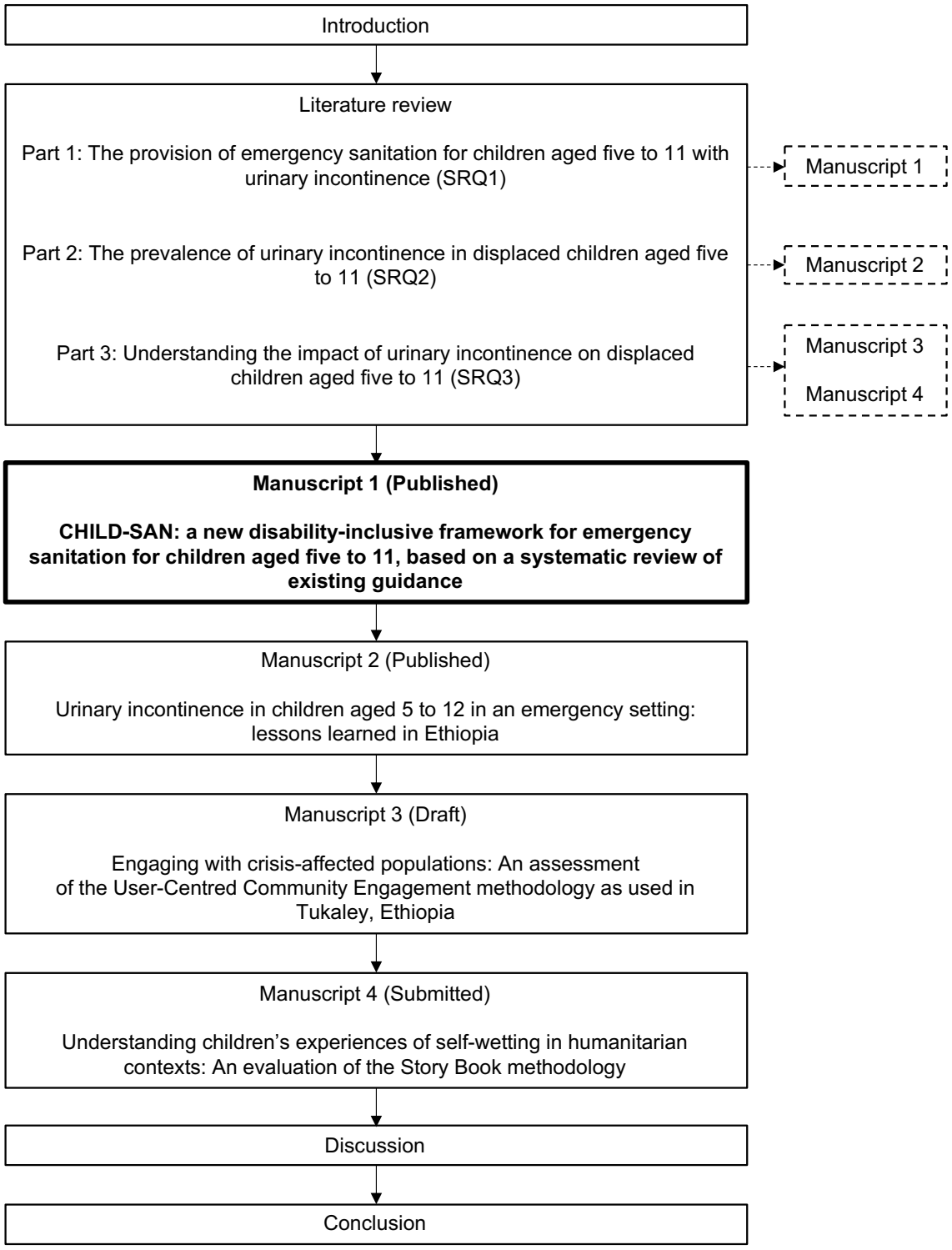
WHO 2018. ICD-11 definition of Enuresis. [Accessed 9 November 2021]. Available from: https://icd.who.int/browse11/l-m/en#/http%3A%2F%2Fid.who.int%2Ficd%2Fentity%2F1157749237.

Yates, T., Allen Vujcic, J., Leandre Joseph, M., Gallandat, K. and Lantagne, D. 2018. Efficacy and effectiveness of water, sanitation, and hygiene interventions in

emergencies in low-and middle-income countries: a systematic review. Waterlines. 37(1).

Yeung, C.K., Sreedhar, B., Sihoe, J.D.Y., Sit, F.K.Y. and Lau, J. 2006. Differences in characteristics of nocturnal enuresis between children and adolescents: A critical appraisal from a large epidemiological study. BJU International. 97(5), pp.1069–1073.

Emergency sanitation for children with urinary incontinence (Rosato-Scott)



Manuscript 1 (Published) (Rosato-Scott et al., 2021a)

Rosato-Scott, C.; Evans, B.E. and Barrington, D.J. 2021. CHILD-SAN: a new disability-inclusive framework for emergency sanitation for children aged five to 11, based on a systematic review of existing guidance. Journal of International Humanitarian Action. **6**(1)

Note: The following version has been amended for the purposes of PhD submission. Please see Appendix A4 for the published version.

Abstract

The specific sanitation needs of children aged five to 11 years old – those too old to use small potties, but usually too young to safely and confidently use adult latrines during both the day and night, and including children in this age range with disabilities – have often been overlooked in the provision of emergency sanitation. There are multiple reasons to provide sanitation specifically for this age group. They represent a large number of beneficiaries; legal principles and the moral obligations of humanitarian actors should drive their inclusion. Failure to consider their needs results in increased risk of injuries, abuse and/or exploitation when using unsuitable locations to urinate or defecate, and negative health impacts arising from being unable to manage personal hygiene.

We have critically reviewed existing guidance for the provision of emergency sanitation for children aged five to 11 and subsequently present a new disability-inclusive framework: CHILD-SAN. CHILD-SAN is an acronym representing key factors for the water, sanitation and hygiene (WASH) sector to consider in emergency sanitation programmes: **c**hild participation, **h**eights, user-fr**i**endly, **l**ocation, **d**écor, **s**caled-down, **a**ccessibility, and mo**n**itoring and evaluation.

The CHILD-SAN framework recommends (a) safe and meaningful child participation in emergency WASH prepared- ness planning and emergency WASH programming as a means to develop contextually-appropriate facilities, (b) specific design considerations for child-friendly toilets (that is, they meet the needs of a child), and (c) the collection of sex-, age- and disability-disaggregated data against contextually appropriate indicators to determine the prevalence of child-friendly facilities and their use. We found few examples of emergency WASH programmes adhering to elements of the CHILD-SAN framework, but the implementation of CHILD-SAN would contribute to the WASH

sector's aims of achieving universal sanitation and maximising opportunities for good health, dignity, comfort and safety for all.

Context

An 'emergency' is a subjective concept which can be defined as 'a situation that threatens the lives and well-being of large numbers of a population and requires extraordinary action to ensure their survival, care and protection' (UNICEF 2010, p.4). In an emergency, community and state institutional structures and services are ruptured, and families and communities are broken-up or displaced (Tanner and O'Connor 2017). In such contexts, children are particularly vulnerable. The Core Commitments for Children in Humanitarian Action outline programme commitments for the initial response to an emergency, with the water, sanitation and hygiene (WASH) sector aiming to prevent and reduce mortality and morbidity by minimising the spread of disease (UNICEF 2010). In addition, WASH actors are expected to ensure that all people have access to adequate and equitable sanitation and hygiene, and the maximisation of opportunities for good health (defined by the World Health Organisation (WHO) as complete physical, mental and social well-being), dignity, comfort and safety (WHO 2006; United Nations 2016; Sphere Association 2018; Groupe URD 2019). Whilst these aspects should be considered from the beginning, increasing attention and time will be spent on ensuring their achievement over time.

There has been a reasonable amount of research into how emergency WASH interventions provide sanitation for both children under-5 years old (due to the significant health risks their faeces represent) and adults (aged 18 years and over) during both the initial and longer-term response. Yet the specific sanitation needs of those too old to use small potties but usually too young to safely and confidently use adult toilets during both the day and night (defined for our purposes as aged from 5 to 11 years old), and including children with disabilities, are often overlooked (Visser 2012).

Children and emergencies

Cultural definitions of the upper limit of childhood may vary, but the United Nations (UN) Convention on the Rights of the Child (CRC) defines a child as 'every human being below the age of 18 years unless under the law applicable to the child, majority is attained earlier' (Part I, Article 1) (UN 1990). While the specifics of definitions may vary, the general point remains; children are particularly vulnerable in an emergency and children under 15 'suffer the most' (Global WASH Cluster 2019, p.7).

The United Nations Office for the Coordination of Humanitarian Affairs (OCHA) estimates that in 2021, 235 million people will need humanitarian assistance and protection. This means 1 in 33 people worldwide needs help (OCHA 2020, p.9). At the end of 2019, the United Nations High Commissioner on Refugees (UNHCR) estimated that there were 87.63 million persons of concern, being any person whom the UNHCR considers to be a refugee, a returnee, stateless, internally displaced or an asylum-seeker (UNHCR 2020). Of these, the UNHCR had demographic data on 36 million: over half (19 million) were under 18 years of age, and 1 in 5 (7.86 million) were aged between 5 and 11 years of age (UNHCR 2020).

During the disruption of an emergency children of any age and ability face a range of heightened risks—particularly if separated from family and/or caregivers—including disease, a disrupted education, gender-based violence including sexual violence and exploitation, malnutrition, neglect, physical and emotional abuse, psychosocial distress, trafficking and recruitment into armed groups (Tanner and O'Connor 2017; Sphere Association 2018; UNICEF 2018). Further, whilst usually dependent on others to provide their needs, including safe food and water, shelter and healthcare, in an emergency children may necessarily be dependent on adults who are not be part of their usual network of caregivers.

The Core Commitments for Children in Humanitarian Action (CCCs) are a global framework for humanitarian action for all children guided by international human rights law (including the Convention on the Rights of the Child and international humanitarian law), and based on global standards and norms for humanitarian action (UNICEF 2010). The CCCs outline the programme commitments for action in the first 8 weeks of an emergency response and provide guidance for action beyond that period by six sectors: nutrition, health, HIV and AIDS, education, child protection, and WASH (UNICEF 2010).

The WASH sector in an emergency

Oxfam (2013, p.4) considers that 'WASH' incorporates water (clean water supply for human consumption, hygiene and household needs), sanitation (excreta disposal, solid waste management, drainage and vector control) and hygiene (community mobilisation and engagement, information, education and communication, non-food item distributions and health data monitoring). In the first stages of an emergency response, the core mandate of WASH interventions is to prevent and reduce mortality and morbidity by minimising the spread of disease, primarily through the separation of humans from faecal matter. They are 'not necessarily intended to provide long-term sustainable access, but instead provide rapid relief' (Yates et al. 2018, p.32).

The WHO recognises four stages of response to an emergency, with timings being context-specific: first steps (normally the first week), emergency response (normally the first month), continuing response/consolidation (beyond the first month) and phasing out/recovery (WHO 2008). WASH interventions must adapt as the emergency progresses to beyond providing 'rapid relief' in the initial (first steps and emergency response) phases. In the continuing response/consolidation phase, efforts aim to shift from the provision of communal solutions to culturally appropriate and sustainable household-level solutions informed by the equitable participation of the affected population (Gensch et al. 2018). During the phasing out/recovery phase, infrastructure development continues and the participation of stakeholders continues to increase, to facilitate handover to households or local and longer-term partners (Gensch et al. 2018).

Humanitarian Response Plans (HRPs) are prepared for a protracted or sudden onset emergency that requires international humanitarian assistance (OCHA 2019). Initially prepared for a year, they are annually updated as the emergency progresses: the average length of an HRP, and therefore the associated emergency response, is 9.3 years (OCHA 2018). During that time, there will be multiple WASH interventions, with differing objectives. The Sphere Handbook (Sphere Association 2018) is generally considered by the humanitarian sector to represent best practice guidance for the delivery of emergency sanitation interventions. Sphere states that a key activity of emergency WASH interventions is 'ensuring conditions that allow people to live with good health, dignity, comfort and safety' (Sphere Association 2018, p.92), with the WHO defining health as 'a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity' (WHO 2006). Further, the Sustainable Development Goals (SDGs) aim to 'achieve access to adequate and equitable sanitation and hygiene for all ... paying special attention to the needs of women and girls and those in vulnerable situations' by 2030 (SDG Target 6.2) (United Nations 2016). Prior to the SDGs, the main priority had been the provision of basic sanitation at the household level with other settings receiving less attention: to achieve universal access other settings now need to be considered, including those of involuntarily displaced populations (Behnke et al. 2018).

It is within this context that we seek to (a) critically review existing guidance for the provision of emergency sanitation for children specifically aged five to 11 (being those too old to use small potties, but usually too young to safely and confidently use adult toilets during both the day and night, including children with disabilities), (b) present a new disability-inclusive framework (CHILD-SAN) that the WASH sector can use to better provide emergency sanitation for this somewhat forgotten age group and (c) critically assess existing facilities against the CHILD-SAN framework.

Methods

Systematic review

A systematic method was used to search for publications which (a) discussed or reported on emergency sanitation for children; (b) were published in 2004 or later, being the year that the Sphere Handbook (Sphere Association 2018) first included children as a cross-cutting theme; and (c) were written in English or Spanish (being the languages spoken by the lead author) (Criterion 1). Full texts of publications that met Criterion 1 were assessed to determine whether they provided guidance on (Criterion 2a) and/or reported on the provision of emergency sanitation for children (Criterion 2b), including those aged five to 11. The publications which met Criterion 2a and/ or b were qualitatively analysed (Fig. 1).

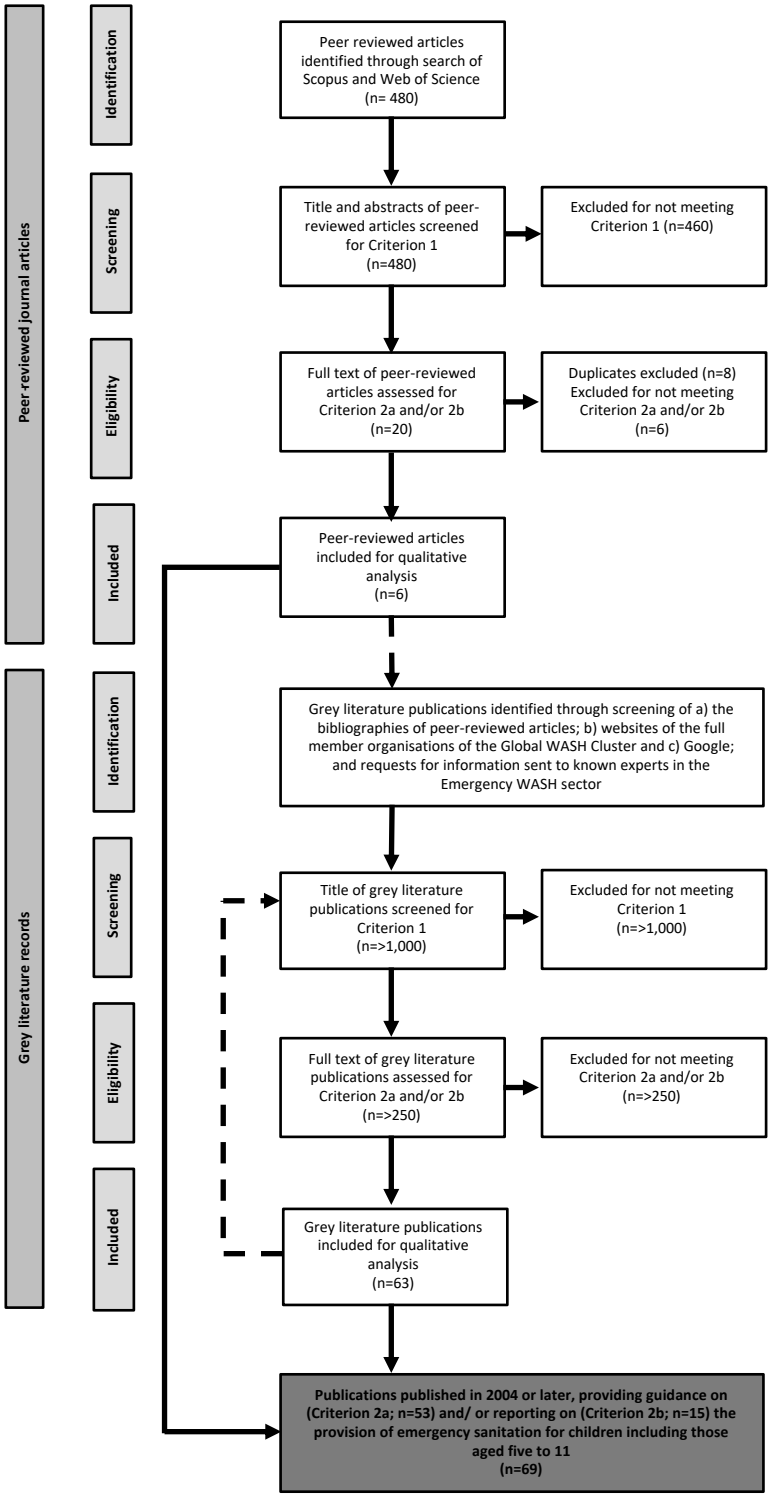


Fig.1 Systematic review: methodology

Process of identifying peer-reviewed and grey literature publications for review. Criterion 1 being publications which (a) discussed or reported on emergency sanitation for children, (b) were published in 2004 or later, and (c) were written in English or Spanish. The 69 publications that met Criterion 2 were classified as either providing guidance on (Criterion 2a) or reporting on (Criterion 2b) the provision of emergency sanitation for children aged five to 11 (see Supplementary Information Table 1). The dashed lines

indicate where bibliographies were used to identify further publications. The figure was developed from the PRISMA Statement (Moher et al. 2009).

A search of the peer-reviewed literature was conducted on March 3, 2019. The Scopus and Web of Science databases were searched for articles published since 2004 using the search string '(emergency OR disaster OR humanitarian OR crisis) AND (sanitation OR toilet OR latrine OR 'solid waste management') AND (child*)' which returned 247 and 233 results, respectively. The titles and abstracts (where necessary) of these records were screened according to Criterion 1, resulting in 21 articles from which eight duplicates were removed. Each article was then assessed to determine whether it met Criterion 2a and/or 2b, of which six did.

To identify grey literature records for inclusion the following were screened: (a) bibliographies of the six peer-reviewed articles which met Criterion 2a and/or 2b; (b) the websites of the 41 organisations that are full members of the Global WASH Cluster[11]; and (c) Google using the search term 'emergency sanitation children' (with the first 120 results assessed, after which saturation was reached as results were not relevant). Requests for information were also sent to known experts in the Emergency WASH sector, including to an informal email group of individuals with an interest in incontinence in low- and middle-income countries (44 members at time of the request, December 17, 2018), and to the Emergency WASH Google Group which is maintained by the Global WASH Cluster and USAID (227 members at time of the request, March 13, 2019). The

[11]The 41 organisations that are full members of the Global WASH Cluster are Action contra la Faim, Adventist Development and Relief Agency, Care International, Catholic Agency for Overseas Development, Catholic Relief Services, Clean the World Foundation, Concern Worldwide, German WASH Network, GOAL, International Federation of Red Cross and Red Crescent Societies, International Medical Corps, IMPACT Initiatives, International Organisation for Migration, International Rescue Committee, Islamic Relief, Medair, Mentor Initiative, Mercy Corps, Norwegian Church Aid, Norwegian Refugee Council, Oxfam International, Plan International, Polish Humanitarian Action, Population Services International, Red Cross Austria, Relief International, Samaritan's Purse, Save the Children UK, Solidarites International, Tearfund, Terre des Hommes, THW (Germany), World Vision, UN Development Programme, UN Environment Programme, UN Habitat, UN Refugee Agency, UN International Children's Emergency Fund, UN Relief and Works Agency, World Food Programme and World Health Organisation.

full text of each publication that met Criterion 1 was assessed to determine whether it met Criterion 2a and/or 2b.

The bibliographies of all grey literature publications that met Criterion 2a and/or b were screened for publications that met Criterion 1, with the full text of those that did assessed to determine if they met Criterion 2a and/or b. This process was repeated until no new publications were identified.

Analysis of publications that met Criterion 2a (leading to the development of the CHILD-SAN framework)

Publications that provided guidance on the provision of emergency sanitation for children including those aged five to 11 (Criterion 2a) were inductively coded using NVivo 12. The codes (Table 1) assigned a summative attribute to a portion of data.

Table 5 Codebook for Criterion 2a publications

Code	**Definition of the text to which the code relates**
Definitions	Definitions of key terms
Emergency statistics	Key data points related to emergencies
Guidance, general	General guidance for emergency WASH interventions
Guidance, M&E	General guidance for the monitoring and evaluation of emergency interventions
Response phases	Descriptions of emergency response phases
Response principles	General principles guiding the WASH-sector's response to emergencies
Solid waste management	Any reference to children and solid waste management
Toilets	Any reference to children and toilets (including latrines)

Within each code, emerging themes were identified and pertinent excerpts which were specifically relevant to children aged five to 11 were highlighted. The identified themes across the codes were amalgamated with each becoming an element represented by the acronym CHILD-SAN, being **c**hild participation, **h**eights, user-fr**i**endly, **l**ocation, **d**écor, **s**caled-down, **a**ccessibility, and mo**n**itoring and evaluation.

Analysis of publications that met Criterion 2b (leading to an assessment of reported emergency sanitation against the CHILD-SAN framework)

The publications that reported on the provision of emergency sanitation for children including those aged five to 11 were also inductively coded using NVivo 12. The codes (Table 2) assigned a summative attribute to a portion of data and this system was used to identify examples of emergency sanitation for children aged five to 11, or the monitoring and evaluation of emergency sanitation for children aged five to 11.

Table 6 Codebook for Criterion 2b publications

Code	Definition of the text to which the code relates
Examples, M&E	Real-life examples of the M&E of emergency interventions
Examples, sanitation	Real-life examples of emergency sanitation for children
Use of toilets statistics	Data points related to the use of toilets by children

Once identified, these examples (of emergency sanitation for children aged five to 11, or the monitoring and evaluation of emergency sanitation for children aged five to 11) were assessed against the newly developed CHILD-SAN framework. The assessment noted if the examples referred to any of the elements that the acronym CHILD-SAN represents, being **c**hild participation, **h**eights, user-fr**i**endly, **l**ocation, **d**écor, **s**caled-down, **a**ccessibility, and mo**n**itoring and evaluation. Further, the assessment then noted if the elements identified adhered to the recommendations of the CHILD-SAN framework or not.

Note that some publications provided guidance on (Criterion 2a), and reported on (Criterion 2b), the provision of emergency sanitation for children including those aged five to 11. These publications were therefore coded twice.

Findings

The definition of 'sanitation'

The WHO defines sanitation as 'the provision of facilities and services for the safe management of human excreta ... (and) also includes the safe management of solid waste and animal waste' (WHO 2018). Some authors of reviewed publications, including this one, prefer to broaden this definition from the protection of personal, public and environmental spaces: Langford et al. (2017, pp.348–349) for example, add that sanitation is also 'the ability to effectively access space and facilities (whenever and wherever needed) that afford privacy, dignity and safety in which to urinate, defecate and

practice related hygiene, including menstrual health management, in a culturally acceptable manner.'

There is an extensive and diverse literature providing guidance for the delivery of emergency sanitation interventions. Emergency sanitation for children is referenced in varying degrees throughout the literature, but needs at different ages are rarely considered. Most guidance focuses on participation in behavioural change programme design (especially for hygiene management programmes, usually hand-washing before touching food and after contact with excreta) and excreta management (largely for children under the age of five) and hygiene promotion. Specific considerations for children aged five to 11 were found only with regard to the provision of toilets and handwashing facilities. Note that we have used the term 'toilet' to mean any 'facility or device that immediately contains excreta and creates the first barrier between people and the waste' (Sphere Association 2018, p.113).

A critical review of existing guidance

Guidance for the provision of emergency sanitation for children aged five to 11 generally fell into three categories: ensuring safe access, adaptations to facilitate use, and improving a child's experience of using a toilet.

Ensuring safe access

For a child to be able to use a toilet they must be able to safely access it, and the guidance notes that paths should be wide enough for two people (for example, a caregiver and child) to comfortably pass (Ferron and Lloyd 2014). We note that caregivers may not always be available or willing to accompany a child to the toilet however, for example, in cultures where the practice of *Purdah* is followed such as the Rohingya community in Cox's Bazar, Bangladesh (House 2019). Therefore, the ability of a lone child to navigate the approach (both in terms of distance and topography) must also be considered.

Adaptations to facilitate use

The guidance acknowledges that toilets need to be adapted for the use by children with disabilities, and because children are smaller and have less physical strength relative to adults (UNICEF 2012). Features to be adapted include the heights of door handles, locks and handrails (Save the Children 2013); toilet seat and squatting plate dimensions (Banzet 2003; Ferron and Lloyd 2014); the size of drop-holes (Noortgate and Maes

2010); and the ease of use of doors, taps for handwashing and water for anal cleansing (Zomerplaag and Moojiman 2005).

Within the existing guidance for emergency sanitation for children aged five to 11, UNICEF (2017b) provides indicative sizings for adaptations to be made to toilets for children with disabilities; Noortgate and Maes (2010) provide indicative child-friendly (that is, they meet the needs of a child) latrine slab sizings (a latrine slab is a cover for the latrine pit with a hole to the pit below; users stand on the slab when using the latrine). In Zomerplaag and Moojiman's (2005) guidance for child-friendly hygiene and sanitation facilities in schools, they state that it is not possible to set international standards for facility dimensions because the heights and sizes of children will vary. Instead, they advocate conducting a participatory exercise to determine contextually appropriate dimensions. Whilst this is an ideal approach and should always be conducted, such an exercise may not be possible in the initial (first steps and emergency response) phases of an emergency and the user population may also be frequently changing. As the absence of technical guidance may deter adaptations or result in unsuitable adaptations, we have used the indicative sizings as recommended by UNICEF (2017b), but we encourage the participation of children to improve the designs and to ensure that they are contextually appropriate.

Improving a child's experience of using an emergency toilet

Spaces such as toilets provide child (and adult) users with a range of positive and negative experiences related to colours, smells, shapes and sounds (UNICEF 2012). The guidance suggests a number of ways to improve a child's experience of using emergency toilets, including a higher ratio of facilities to children than for adults to lower waiting-times (Noortgate and Maes 2010; Ferron and Lloyd 2014), enough space for both the child and carer (UNHCR 2018a), open and light structures (Zomerplaag and Moojiman 2005; Deniel 2006) and bright décor (Zomerplaag and Moojiman 2005).

The guidance often assumes that the primary caregiver is the mother, and some guidance recommends positioning gender-neutral children's toilets near to adult female toilets (SuSanA 2012). However, primary caregivers will not always be female, and it may be contextually appropriate to also position gender-neutral children's toilets near to adult male toilets. Yet an 8-year-old girl with a male caregiver may feel uncomfortable using a toilet located close to the adult male toilets and may also feel uncomfortable using a gender-neutral children's toilet located close to the adult female toilets alone and potentially with boys. This emphasises the need for community participation in the design

and location of facilities as soon as possible to determine what is culturally and contextually appropriate.

CHILD-SAN: a new disability-inclusive framework for emergency sanitation for children aged five to 11

Using and building upon the existing guidance, we present a new framework for the provision of emergency sanitation for children aged five to 11: CHILD-SAN. CHILD-SAN is an acronym that the WASH sector can use to better provide sanitation facilities for children to use, and includes a number of specific considerations when designing toilets for this age group (Table 3). It is a disability-inclusive framework, that is, it promotes the construction of toilets that are accessible to all children within this age group, following the principles of universal design (UNICEF 2017a).

Table 3 CHILD-SAN: a new disability-inclusive framework for emergency sanitation for children aged five to 11

C	**C**hild participation	- Ensure (a) safe, meaningful and disability-inclusive child participation in emergency WASH preparedness planning and (b) meaningful and disability-inclusive participation in emergency WASH programming from the earliest opportunity that it is safe to do so using existing guidelines (notably O'Kane 2013a) - *See The case for CHILD-SAN facilities section for discussion*
H	**H**eights	- Door handles (if being used) should be mounted 800 to 900 mm above the floor (UNICEF 2017a) - Locks (if being used) should be positioned within reach of a child or wheelchair user, at a height of between 680 mm and 800 mm (Save the Children 2013; UNICEF 2017a) - Grab rails on each side of the toilet should be located 300 to 350 mm from the centre of the toilet and between 510mm and 640 mm off the ground (UNICEF 2017a) - Water taps should be positioned within reach of a child or wheelchair user, at a height of between 680 to 800 mm (UNICEF 2017a) - Washbasins (with unobstructed knee clearance for wheelchair users) should be positioned at height of between 650–700 mm and 200 mm deep (UNICEF 2017a)
I	user fr**i**endly	- Consider if (verbal or visual, using simple communication methods) guidance on how to use the toilet needs to be provided

		- Children are often not prepared to wait, or do not have sufficient bowel or bladder control to wait, and pits may also fill-up relatively more quickly as children drop items down the hole both on purpose and accidentally (Ferron and Lloyd 2014). A ratio of 1 toilet per 20 children is recommended (Noortgate and Maes 2010) - Allow for a spare 0.5 m of depth in the latrine pit size to avoid unpleasant sights and excreta splashing out during use. A pit with a maximum depth of 2 m (an effective depth of 1.5 m) will therefore last for about 2 years if it is used normally by 20 children (an accumulation rate of 0.04 m^3/child) (Noortgate and Maes 2010) - Consider how open the toilet should be. Children, particularly younger children, may prefer an open structure without a door, roof (this may be climate-dependent) or superstructure (Deniel 2006). Such structures alleviate fears of the dark, and younger children also like to imitate and observe others (Zomerplaag and Moojiman 2005) - Provide enough space for two people (for example, a caregiver and child) to use the toilet to enable supervision, help and teaching (UNHCR 2018a), and that accommodates a wheelchair turning radius (1500 mm by 1500 mm) (UNICEF 2017a) - Ensure that doors (if being used) are robust but not too heavy for children to use (Zomerplaag and Moojiman 2005). D-lever door handles are preferred rather than doorknobs (Jones and Wilbur 2014; UNICEF 2017a) - If a toilet seat or chair is being used, grab rails should be provided on each side of the toilet. One should be moveable or foldable on one side to allow for transferring (UNICEF 2017a) - Provide a handle bar and/or handrails to support squatting. Multiple handrails may be needed (vertical, horizontal, various heights) (Noortgate and Maes 2010; Ferron and Lloyd 2014; Jones and Wilbur 2014) - Provide doors with locks and walls that ensure privacy; easy access to water; hooks and shelves; and discrete disposal facilities to aid the changing of soiled menstruation and incontinence products and clothing. Note that the whole collection and disposal chain of soiled items also needs to be considered

		(Sommer et al. 2017) - Ensure that taps are robust but not too heavy for children to use (Zomerplaag and Moojiman 2005). Large taps with long levers are easier to operate (UNICEF 2017a) - Locate soap for ease of use and where a child with visual or mobility disabilities can easily find/reach it (UNICEF 2017a)
L	**L**ocation	- Consider (distance/location) where to safely position gender-neutral and gender-segregated children's toilets that is culturally appropriate for both the child and caregiver
D	**D**écor	- Brightly decorated walls can encourage use, and decoration with child-friendly hygiene promotion material can increase awareness at the same time (Zomerplaag and Moojiman 2005) - Decoration can include 'nudges' to use handwashing facilities, for example, footsteps from the toilet to the hand- washing facilities - Involving children in decoration can encourage a sense of ownership and deter vandalism (SuSanA 2012)
-		
S	**S**caled-down	- Drop-holes should not be so big that a child could fall-in, or be fearful of falling-in: Noortgate and Maes (2010, p.31) provide an indicative diameter of 120 mm - Toilet-seats should be low (350 to 450 mm from floor level) (UNICEF 2017a) or a step provided for children to access the toilet-seat (Banzet 2003) although this may limit access for children with disabilities - Squatting plate dimensions (including the distance between footrests of a squatting platform and the distance from a squatting platform to the wall) should be suitable for a child; indicative dimensions have been provided by Noortgate and Maes (2010, p.31). Smaller squatting plates can be fixed over adult ones (UNICEF 2017b)
A	**A**ccessibility	- Consider accessibility for both the child and caregiver - Position well-lit signs to show the location of the toilets at both adult and child-height, and use simple communication methods, for example, symbols (UNICEF 2017a) - Paths should be wide enough for two people (for example, a caregiver and child) to comfortably pass (Ferron and Lloyd 2014),

		and ideally 1800 mm wide to allow two wheelchair users to pass (UNICEF 2017a) - Distances and topography of paths must be appropriate for all children and caregivers to navigate - Line paths with painted rocks and provide painted landmark posts to increase visibility (Jones and Wilbur 2014) - Ramps are the preferred solution for access to at least some of the facilities and where used they should have a minimum width of 1000 mm with raised, painted sides (to avoid falling and to increase visibility) and painted handrails recommended for slopes steeper than 1:20 (Jones and Wilbur 2014; UNICEF 2017a) - If there are steps, the step riser height (150 to 170 mm) and step depth (280 to 420 mm) should be suitable for a child, the step surface should be textured to prevent slippage, and a painted handrail provided for visible support (Ferron and Lloyd 2014; Jones and Wilbur 2014) - Entrances should have a minimum width of 800 mm to allow wheelchair access with no thresholds or barriers on the ground (UNICEF 2017a) - Doors (if being used) should open outwards (Jones and Wilbur 2014)
N	Mo**n**itoring and evaluation	- Ensure the collection of sex-, age- and disability-disaggregated data against contextually appropriate indicators— including the WASH and Child Protection indicators of the Minimum Standards for Child Protection in Humanitarian— to indicate the prevalence of child-friendly facilities and their use - Consider if cleaning and maintenance exploits children and/or discriminates against girls (Save the Children 2013) *See CHILD-SAN: a new disability-inclusive framework for emergency sanitation for children aged five to 11section for discussion*

An assessment of existing toilets against the CHILD-SAN framework

For a child to use an emergency toilet, they must (a) want to use it and (b) be able to use it. The premise of the CHILD-SAN framework is that it will result in toilets that children aged five to 11 will want, and are able, to use. The assumption is that the collection of usage data will indicate the prevalence of such facilities: usage will be higher if facilities adhere to the recommendations of the CHILD-SAN framework.

The UNHCR monitors and evaluates WASH conditions for all recognised refugee and internally displaced people (IDP) settlements, with initial 'emergency standards' (general guidance is that these are for use up to and including the first 6 months after population movement has stabilised, but definition is context-specific), and longer-term 'post-emergency standards' subsequently (UNHCR 2018b). Additional monitoring frameworks may also be used according to context, for example, to incorporate national standards and/or to include specific field indicators. The UNHCR Core WASH Indicators and associated minimum standards related to toilets are as follows:

- Number of persons per toilet, noting that toilets should be facilities that are cleanable, guarantee privacy and are structurally safe (Emergency standard 1:50/post-emergency standard 1:20 aiming for one latrine per household as soon as possible)
- Percentage of households with household toilet (post-emergency standard 85%)
- Percentage of households reporting defecating in a toilet (emergency standard 60%/post-emergency standard 85%)
- In schools, 50 pupils per toilet on average, being 30 girls per toilet and 60 boys per toilet with additional urinals provided for boys
- In healthcare facilities, 20 outpatients per toilet, and 10 inpatients/beds per toilet (UNHCR 2018b).

Sphere recommends disaggregating data 'to the extent possible and with categories appropriate to the context to understand differences based on sex or gender, age, disability, geography, ethnicity, religion, caste or any other factors that may limit access to impartial assistance ... for general data on age use the same cohorts as in national data-collection systems' (Sphere Association 2018, p.12). In the absence of national age cohorts, Sphere recommends the age brackets 0 to 5 years, 6 to 12 years, and 13 to 17 years for children (Sphere Association 2018, p.13). Yet Mazurana et al.'s (2013) review of the collection of sex-and age-disaggregated data (SADD) in humanitarian responses found that the collection of SADD was 'extremely limited, ad hoc and sporadic' (p.S77). Further, even when SADD is collected, the majority of those interviewed believed that 'field officers do not necessarily know what to do with it' (Mazurana et al. 2013, p.S78). House (2019) also found that in Cox's Bazar, Bangladesh, although the Gender in Humanitarian Action (GiHA) cross-sectoral group had been encouraging the collection of SADD, it had overlooked data on disability.

Mazurana et al.'s and House's findings were reflected in the lack of data we found on the provision and use of toilets by children aged five to 11. Although anecdotal evidence

of CHILD-SAN facilities (or the lack thereof) was noted, no quantitative data was found. Positive reports, *with the CHILD-SAN attributes acknowledged noted in **bold** where sufficient detail is provided*, included the following:

- In Rwanda in 1994, open child latrines with smaller squat holes were provided in IDP camps to be used by children aged two and older. Similar latrines were used in IDP camps in Uganda in 2006 (Harvey 2007) (CH**I**LD-**S**AN)
- Dropholes with dedicated cubicles for children were installed in the Petion Ville Golf Course camp in Port-au-Prince, Haiti (Bastable and Lamb 2012) (CHILD-SAN unknown)
- Yates et al. (2018) conducted a systematic review on the efficacy and effectiveness of short-term WASH interventions in emergency responses in low- and middle-income countries. The review found that when designing latrines, specific consideration for women and vulnerable populations including children were documented in South Sudan, India, and Liberia. This led to more appropriate latrine designs with marginal additional costs (CHILD-SAN unknown)
- In the informal tented settlements of the Bekaa Valley, Lebanon, locks at child-height were added to the latrines (Jabbar 2018) (C**H**ILD-SAN)
- The UN Children's Fund (UNICEF) is trialling an accessible latrine slab for emergencies in Angola with users to include children (UNICEF 2017b) (CH**I**LD-**S**AN).

Negative anecdotes, *with the CHILD-SAN attributes not acknowledged noted in **bold** where sufficient detail is provided*, included:

- In the Bahn refugee camp in Nimba, Liberia, 700 children aged five to ten were identified, but the WASH programme evaluator had no information that their specific sanitation needs were addressed outside of the schools (Visser 2012) (CHILD-SAN unknown)
- In Ferron and Lloyd's (2014) study of emergency sanitation for children, 29% of respondents had provided child-friendly toilets in schools, but only 16% had provided child-friendly toilets in community settings. Whereas child-friendly WASH facilities were sometimes provided in health centres and most often provided in child-friendly spaces (CFSs, safe places for children). Further, informants noted that the needs of different age groups of children were not considered (CHILD-SAN unknown)
- In the province of Leyte in the Philippines post-typhoon Haiyan, children aged between 2 and 7 years old reported finding ceramic bowl toilets difficult to use and were sometimes afraid of using the 'Comfort Rooms' due to the lack of

handrails, an unfamiliarity with using a ceramic bowl toilet, not liking the feel of the ceramic bowl toilet and/or a fear of sitting on it, and a fear that the toilet hole was too big (Denis 2015) (CH**I**LD-**S**AN)

- In Cox's Bazaar, Bangladesh, women reported giving their children less food to avoid using the latrine at night (Farrington 2018) (CHILD-S**A**N)
- Also in Cox's Bazar, House (2019) noted that, in one CFS visited that although the toilet units themselves were well designed for children, the entrances to the male and female toilet doors were situated together behind the same wall without a division, so that males had to walk by the female door to access the male urinals (CHI**L**D-SAN)
- Bedwetting by children has been noted by NGO workers in refugee camps (Veneme 2015; Farrington 2019; House 2019). Whilst some children may be experiencing urinary incontinence (the involuntary leakage of urine during the day and/or at night), some instances may be due to a reluctance to use the existing facilities (social incontinence) (CHILD-SAN unknown).

The lack of quantitative data can be attributed to a multitude of reasons, not least the challenges of collecting data in emergency contexts and the prioritisation of response activities (Yates et al. 2018). But as Mazurana et al. (2013, p.S79) concluded, 'the additional time and resources needed to (collect SADD) are justified by the improvements in programming and by avoiding costly programme failures due to errors in targeting and design.'

We reiterate Mazurana et al.'s (2013) recommendation that SADD is collected in all phases of an emergency to inform the response and further expand this to include data disaggregated by disability (assessed using the Washington Group/UNICEF child functioning question set) as recommended by the Age and Disability Consortium (ADCAP) (Age and Disability Consortium 2018) (Table 3). Collecting data to determine the percentage of households reporting defecation in a toilet disaggregated by sex, age and disability would indicate the prevalence of child-friendly facilities and their use, the assumption being that usage would be higher if facilities addressed the CHILD-SAN recommendations. It is also recommended that the WASH and Child Protection indicators and targets of the Minimum Standards for Child Protection in Humanitarian Action are adapted to the context and used in conjunction with the Sphere standards as soon as possible (Table 3). Those related to toilets are as follows:

- Percentage of WASH projects where child safety and wellbeing are reflected in the initial risk assessment, design, monitoring and evaluation framework (Target 100%)

- Percentage of surveyed sites with separated communal facilities (toilet and bathing facilities) for girls/ women and boys/men (Target 100%)
- Percentage of surveyed sites with communal facilities that meet 90% of safety criteria (Target 100%, safety criteria defined using in-country checklist)
- Percentage of schools, play areas, health centres etc., that include child-appropriate WASH facilities (Target 100%, child-appropriate defined in-country)
- Percentage of accessible WASH facilities (for children with disabilities, adolescent girls) (Target 100%) (The Alliance for Child Protection in Humanitarian Action 2019)

The recommendation to consistently use known standards in monitoring frameworks aligns with the initial findings of the Quality Assurance and Accountability Project (QAAP), which is an ongoing Global WASH cluster initiative to determine how best to measure quality in humanitarian WASH responses (Brown 2019).

The case for CHILD-SAN facilities

If there are many reasons why child-friendly toilets for children aged five to 11 are not always provided, and why data disaggregated by sex, age and disability is not always collected and/or actioned to determine if they are being provided and used, there are just as many reasons advocating for CHILD-SAN facilities. The first is the sheer number of beneficiaries: in 2019, 1 in 5 known persons of concern were aged between 5 and 11 years of age (UNHCR 2020).

If there are facilities available but a child does not want to or cannot use them, they may choose to urinate and defecate elsewhere instead, for example, outside or within a shelter. House (2019) found that some children in the Cox's Bazar refugee camps (Bangladesh) were fearful of using the toilets, but urinating or defecating elsewhere may also expose the child to risks of injuries, abuse and/or exploitation (UNICEF 2017a). Habitually delaying urination until a suitable place is found also increases the risk of developing urinary incontinence (the involuntary leakage of urine) due to bladder dysfunction (Zhou et al. 2019). A child may also urinate or defecate on themselves instead of using what is felt to be an unsuitable toilet, which is known as 'social incontinence' (Ryan 2018). Children that wet themselves can suffer from incontinence associated dermatitis (IAD; similar to nappy rash), skin infections, pressure sores, urinary tract infections and dehydration (if fluid restriction is used as a management strategy) (Rosato-Scott et al. 2019). The social and emotional impact on their lives and their carers' lives can also be significant: any resultant personal embarrassment and

shame, or social ostracism (for example, due to smell) can prevent participation in programming, education and social activities (Hafskjold et al. 2016).

There are also legal arguments. The Convention on the Rights of the Child states that 'children have the right to ... a clean and safe environment' (Article 24) (UN 1990). Decades later, the Human Rights to Water and Sanitation (HRWS) were recognised by the UN General Assembly on July 28, 2010 (Resolution 64/292), and recognised in international law by the Human Rights Council's Resolution 15/9 on September 30, 2010 (United Nations 2010a, b). Sanitation was later recognised as a distinct and separate human right by the UN General Assembly on December 17, 2015 (Resolution 70/169), which stated that 'the human right to sanitation entitles everyone, without discrimination, to have physical and affordable access to sanitation, in all spheres of life, that is safe, hygienic, secure, socially and culturally acceptable and that provides privacy and ensures dignity' (United Nations 2015).

To achieve this human right, the international community are striving to attain SDG Target 6.2, which aims to 'achieve access to adequate and equitable sanitation and hygiene for all ... paying special attention to the needs of women and girls and those in vulnerable situations' by 2030 (United Nations 2016). Given the broad definition of sanitation that we have used, the provision of CHILD-SAN facilities would support the attainment of the Human Right to Sanitation for children aged five to 11.

Humanitarian actors also have moral obligations – the 'humanitarian imperative' – to take action 'to prevent or alleviate human suffering arising out of disaster or conflict' (Sphere Association 2018, p.28). This is enshrined in the Humanitarian Charter, which all agencies that endorse Sphere commit to (Sphere Association 2018). The provision of CHILD-SAN facilities acknowledges the right to live with dignity that the Humanitarian Charter advocates.

How the WASH sector can improve the provision of CHILD-SAN facilities

Article 12 of the UN CRC states the right of children to be heard and to be taken seriously, and is one of the four general principles of the Convention, alongside the right to non-discrimination, the right to life and development, and the primary consideration of the child's best interests (UN 1990). Further, General Comment Number 12 states that this right 'does not cease in situations of crisis or in their aftermath' (Paragraph 125, United Nations Committee on the Rights of the Child 2009).

There is much literature on the value of child participation, summarised by the General Comment as 'helping children to regain control over their lives, contributing to rehabilitation, developing organisational skills and strengthening a sense of identity' with the caveat that 'care needs to be taken to protect children from exposure to situations that are likely to be traumatic or harmful' (Paragraph 125, United Nations Committee on the Rights of the Child 2009).

There is also much written on (a) the basic requirements of the implementation of a child's right to be heard, the foundational text being the Committee on the Rights of the Child's nine basic requirements of meaningful child participation (Paragraph 134, United Nations Committee on the Rights of the Child 2009), and (b) guidelines on how best to achieve child participation in humanitarian programming (notably O'Kane 2013a).

Yet despite many WASH sector-specific guidelines recommending the participation of children in the design of emergency sanitation facilities – most recently Oxfam's Sani Tweaks series (Oxfam 2018) – and there being 'how to' materials available, few examples were found by either our systematic review of publications or Ferron and Lloyd's study on emergency WASH for children of all ages (Ferron and Lloyd 2014). This gives rise to the question: why are children, including children with disabilities, not being pro-actively involved and invited to participate in WASH programme design?

In 2017, the Humanitarian Innovation Fund (HIF) launched a WASH Innovation Challenge to pilot rapid community engagement for user-centred sanitation. In response, Eclipse Experience (Eclipse) and Save the Children developed a User-Centred Community Engagement (UCCE) methodology to improve the design of latrines and handwashing facilities for users including children aged 5 to 12 years (Eclipse Experience 2019). Oxfam's evaluation of the four projects implemented under the HIF challenge (two of which, in Bangladesh and Iraq, were implemented by Eclipse and Save the Children) found that time can be made to consult in a meaningful way even in short projects and that the use of well-designed, tightly focused surveys with adequate representative sampling can find out much, quickly (Sandison 2017). Challenges for rapid, user-centred community engagement were also noted however, including that when there is restricted project scope at the project proposal and design stage, the possibilities of user-centred design are limited, and that the design of facilities only does not address users' further engagement in the implementation and maintenance of the infrastructure provided (Sandison 2017).

Oxfam concluded that the main potential of greater community engagement during an emergency response may be when projects move out of the acute response phases into

the consolidation (or stabilisation) phase. It was therefore suggested that the initial infrastructure provided is used as a prototype on which the users can provide feedback, noting that this initial infrastructure should always incorporate the design fundamentals of access, dignity, privacy and safety, and be adaptable to ensure that it can become more sustainable (SuSanA 2012; Sandison 2017). O'Kane's (2013b) review of child participation in humanitarian programming similarly found that there are significant constraints to the safe and meaningful participation of children in the very early stages of an emergency response, and that there are more opportunities to strengthen children's participation in emergency preparedness and once the acute response phases have passed.

However, House (2019) found that the danger of relegating issues to 'when we have time' is that they will never be done and believes that even the simple consultation of a few people representing different groups can and should start right from the beginning of an emergency as this can lead to better initial prototypes that can then be improved through more involved participation and feedback.

CHILD-SAN therefore recommends (a) safe, meaningful and disability-inclusive child participation in emergency WASH preparedness planning, and (b) meaningful and disability-inclusive participation in emergency WASH programming from the earliest opportunity that it is safe to do so, using existing guidelines on how best to achieve child participation in humanitarian programming (notably O'Kane 2013a) (Table 3). For example, ensuring field staff have training and skills to communicate with children, including activities and budgets for children's participation in plans, and reporting against the global children's participation indicator (children's participation that is voluntary, safe and inclusive) (O'Kane 2013a). Such an approach will require commitment from 'senior to field levels (and) across agencies' (House 2019). The dissemination of the CHILD-SAN framework to WASH practitioners at all levels aims to raise the profile of the needs of children aged 5–11, which is not prominent in any existing guidance; and it is hoped will encourage an increase in awareness of the needs and commitment by providing an easy-to-use reminder of the key tenets of providing emergency sanitation for children aged five to 11, with associated references when further detail is needed.

Conclusion

We have critically reviewed existing guidance for the provision of emergency sanitation for children aged five to 11 and subsequently presented a new disability-inclusive framework (CHILD-SAN) that the WASH sector can use to better provide sanitation facilities for children. The framework recommends (a) safe and meaningful child

participation in emergency WASH preparedness planning and emergency WASH programming as a means to develop contextually appropriate facilities, (b) specific design considerations for child-friendly toilets and (c) the collection of sex-, age- and disability-disaggregated data against contextually appropriate indicators to determine the prevalence of child-friendly facilities and their use.

We believe that the implementation of CHILD-SAN would contribute to the WASH sector's aims of achieving universal sanitation and maximising opportunities for good health, dignity, comfort and safety for all. Facilities that do not adhere to the recommendations of the CHILD-SAN framework are known to adversely impact the health, comfort and safety of children. Less is known about the impact on dignity, and our next steps will include research to understand the social and emotional impacts of social incontinence on children and their caregivers.

Manuscript 1: References

Age and Disability Consortium (2018) Humanitarian inclusion standards for older people and people with disabilities. https://reliefweb.int/report/world/humanitarian-inclusion-standards-older-people-and-people-disabilities. Accessed 14 Nov 2018

Banzet J (2003) Towards child-friendly latrines in Viet Nam. Waterfront 16:18–19.

Bastable A, Lamb J (2012) Innovative designs and approaches in sanitation when responding to challenging and complex humanitarian contexts in urban areas. Waterlines 31. https://doi.org/10.3362/1756-3488.2012.007

Behnke N, Cronk R, Snel M et al (2018) Improving environmental conditions for involuntarily displaced populations: water, sanitation, and hygiene in orphanages, prisons, and refugee and IDP settlements. J Water Sanit Hyg Dev:1–7. https://doi.org/10.2166/washdev.2018.019

Brown J (2019) Oxfam views & voices: three things we've learned about measuring quality in humanitarian WASH responses. https://viewsvoices.oxfam.org.uk/2019/07/measuring-quality-wash-responses/. Accessed 8 Aug 2019

Deniel K (2006) Children's sanitation in emergencies. Waterlines 24:28. https://doi.org/10.3362/0262-8104.2006.012

Denis J (2015) Sanitation practices for infants and children in emergencies. Dissertation, Cranfield University, Cranfield

Eclipse Experience (2019) User-centred community engagement. http://www.eclipse-experience.com/user-centred-community-engagement. Accessed 8 Mar 2019

Farrington M (2018) Women's Social Architecture Project: phase 1 final report, Cox's Bazaar https://oxfam.app.box.com/s/gmiiqfdn7ntbxeve7fikllywfitnkcjy/file/384891125807. Accessed 11 Dec 2018

Farrington M (2019) Conversation with Claire Rosato-Scott 20 February 2019

Ferron S, Lloyd A (2014) Emergency WASH for children. https://www.elrha.org/wpcontent/uploads/2015/02/2014-10-11-Emergency-WASH-for-Children-Final.pdf. Accessed 1 Nov 2018

Gensch R, Jennings A, Renggli S, Reymond P (2018) Compendium of sanitation technologies in emergencies. https://www.eawag.ch/fileadmin/Domain1/Abteilungen/sandec/schwerpunkte/sesp/Emergencies/compe ndium_emergencies.pdf. Accessed 22 Feb 2019

Global WASH Cluster (2019) Global WASH cluster annual meeting report. Global WASH Cluster, Geneva Groupe URD (2019) Analysis of the capacity of the

WASH sector. https:// www.urd.org/en/publication/analysis-of-the-capacity-of-the-wash- sector-june-2019/. Accessed 1 Aug 2019

Hafskjold B, Pop-Stefanija B, Giles-Hansen C et al (2016) Taking stock: incompetent at incontinence – why are we ignoring the needs of incontinence sufferers? Waterlines 35. https://doi.org/10.3362/1756- 3488.2016.018

Harvey P (2007) Excreta disposal in emergencies. https://wedc.ac.uk/publications/. Accessed 7 Mar 2019

House S (2019) Strengthening the humanity in humanitarian action in the work of the WASH sector in the Rohingya response. https://www.humanitarianlibrary.org/resource/strengthening-humanity-humanitari an-action-work-wash-sector-rohingya-response-gender-gbv. Accessed 25 Mar 2019

Jabbar GA (2018) Gender-based violence in relation to water, sanitation and hygiene in the informal tented settlements of the Bekaa Valley, Lebanon. Dissertation, University of Leeds, Leeds

Jones H, Wilbur J (2014) Compendium of accessible WASH technologies. https://washmatters.wateraid.org/publications/compendium-of-accessible-wash-technologies. Accessed 17 May 2017

Langford M, Bartram J, Roaf V (2017) The human right to sanitation. In: Langford M, Russell AFS (eds) The human right to water: theory, practice and prospects. Cambridge University Press, Cambridge, pp 345–395

Mazurana D, Benelli P, Walker P (2013) How sex-and age-disaggregated data and gender and generational analyses can improve humanitarian response. Disasters 37:S68–S82. https://doi.org/10.1111/disa.12013

Moher D, Liberati A, Tetzlaff J et al (2009) Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. PLoS Med 6:e1000097. https://doi.org/10.1371/journal.pmed.1000097

Noortgate JVD, Maes P (2010) Public Health Engineering in precarious situations. http://refbooks.msf.org/msf_docs/en/public_health/public_ health_en.pdf. Accessed 18 Nov 2018

O'Kane C (2013a) Guidelines for children's participation in humanitarian programming. https://reliefweb.int/sites/reliefweb.int/files/resources/Children_Participation_Humanitarian_Guidelines.pdf. Accessed 31 Mar 2019

O'Kane C (2013b) Review of children's participation in humanitarian programming. https://www.alnap.org/system/files/content/resource/ files/main/children-participation-humanitarian-review.pdf. Accessed 18 Nov 2018

OCHA (2018) Global humanitarian overview 2019. https://www.unocha.org/ global-humanitarian-overview-2019. Accessed 10 Jan 2019

OCHA (2019) Humanitarian response plan. https://www.humanitarianres ponse.info/en/operations/nigeria/humanitarian-response-plan. Accessed 18 July 2019

OCHA (2020) Global humanitarian overview 2021. https://www.unocha.org/ global-humanitarian-overview-2021. Accessed 8 Feb 2021

Oxfam (2013) Oxfam Minimum Requirements for WASH Programmes (MR- WASH). https://policy-practice.oxfam.org.uk/publications/oxfam-minim um-requirements-for-wash-programmes-mr-wash-300134. Accessed 18 Nov 2018

Oxfam (2018) Sani Tweaks. Best practices in sanitation. www.oxfam.org.uk/ sanitweaks. Accessed 31 Mar 2019

Rosato-Scott CA, Giles-Hansen C, House S, et al (2019) Guidance on supporting people with incontinence in humanitarian and low- and middle-income contexts (LMICs). https://wash.leeds.ac.uk/wpcontent/uploads/sites/45/2019/08/Guidance-document_August-2019_Versi on_1.pdf. Accessed 16 Aug 2019

Ryan F (2018) 'It's horrifically painful': the disabled women forced into unnecessary surgery. https://www.theguardian.com/society/2018/ aug/06/disabled-women-surgery-catheter-accessible-toilets. Accessed 27 Feb 2019

Sandison P (2017) We're listening: an evaluation of user-centred community engagement in emergency sanitation. https://oxfamilibrary.openrepository.com/bitstream/handle/10546/620617/gd-listening-commu nity-engagement-emergency-sanitation-050219-en.pdf?sequence=1& isAllowed=y. Accessed 15 Feb 2019

Save the Children (2013) WASH for children in emergencies. https://www. elrha.org/wp-content/uploads/2015/02/Annex-E-Hygiene_Promo tion_September_Newsletter_2013.pdf. Accessed 10 Jan 2019

Sommer M, Schmitt M, Clatworthy D (2017) A toolkit for integrating Menstrual Hygiene Management (MHM) into humanitarian response. https://www.humanitarianlibrary.org/resource/toolkit-integrating- menstrual-hygiene-management-mhm-humanitarian-response. Accessed 26 Feb 2021

Sphere Association (2018) The sphere handbook: humanitarian charter and minimum standards. www.practicalactionpublishing.org/sphere. Accessed 14 Nov 2018

SuSanA (2012) Sustainable sanitation for emergencies and reconstruction situations. www.humanitarianreform.org. Accessed 6 Mar 2019

Tanner S, O'Connor M (2017) A safe place to shine. Creating opportunities and raising voices of adolescent girls in humanitarian settings. https://www.rescue.org/sites/default/files/document/2248/irccompassgloba lreport.pdf. Accessed 14 Mar 2019

The Alliance for Child Protection in Humanitarian Action (2019) Table of indicators: minimum standards for child protection in humanitarian action, 2019 edition. https://alliancecpha.org/en/CPMS_Table_Indicators. Accessed 10 Feb 2020

UNHCR (2018a) UNHCR WASH manual. Practical guidance for refugee settings. http://wash.unhcr.org/unhcr-wash-manual-for-refugee-settings/. Accessed 14 Nov 2018

UNHCR (2018b) UNHCR Core WASH indicators. https://wash.unhcr.org/ unhcr-wash-standards-and-indicators-for-refugee-settings/. Accessed 25 Jan 2019

UNHCR (2020) UNHCR population statistics. https://www.unhcr.org/refug ee-statistics/download/?url=E1ZxP4. Accessed 8 Feb 2021

UNICEF (2010) Core commitments for children in humanitarian action. www.unicef.org. Accessed 30 Nov 2018

UNICEF (2012) Water, sanitation and hygiene (WASH) in schools. UNICEF, New York

UNICEF (2017a) Guidance: including children with disabilities in humanitarian action – WASH. https://training.unicef.org/disability/emergencies/ downloads/UNICEF_WASH_English.pdf. Accessed 22 Feb 2019

UNICEF (2017b) UNICEF target product profile: accessible latrine slab for emergencies. https://www.unicef.org/supply/files/2017.04.05_Accessible_Latrine_Slab_TPP_v2.2.pdf. Accessed 21 Feb 2019

UNICEF (2018) Humanitarian Action for Children 2018. https://www.unicef.org/eca/reports/unicefhumanitarian-action-children-2018. Accessed 14 Mar 2019

United Nations (1990) The United Nations convention on the rights of the child. https://www.unicef.org.uk/what-we-do/un-convention-child-rights/. Accessed 7 Nov 2018

United Nations (2010a) UNGA Resolution 64/292. The human right to water and sanitation. https://undocs.org/en/A/RES/64/292. Accessed 17 Mar 2019

United Nations (2010b) HRC Res 15/9. Human rights and access to safe drinking water and sanitation. https://undocs.org/A/HRC/RES/15/9. Accessed 17 Mar 2019

United Nations (2015) UNGA Resolution 70/169. The human rights to safe drinking water and sanitation. https://undocs.org/en/A/RES/70/169. Accessed 17 Mar 2019

United Nations (2016) Sustainable development goal 6. https://sustainabledevelopment.un.org/sdg6. Accessed 15 Nov 2018

United Nations Committee on the Rights of the Child (2009) General comment on A12 Right to Be Heard. http://www.crae.org.uk/publications- resources/uncrc-general-comment-on-right-to-be-heard-(article-12)/. Accessed 31 Mar 2019

Veneme V (2015) The unlikely sanitary pad missionary. https://www.bbc.co.uk/news/magazine-34925238. Accessed 8 May 2019

Visser M (2012) External evaluation WASH provision in Bahn refugee camp in Nimba, Liberia. https://www.alnap.org/system/files/content/resource/files/main/acf-bahn-camp-liberia-wash-evaluation-report.pdf. Accessed 7 Mar 2019

WHO (2006) Constitution of the World Health Organisation. WHO, Geneva. Accessed 31 Jan 2019

WHO (2008) Managing WHO humanitarian response in the field. https://www.who.int/hac/techguidance/tools/full_manual.pdf. Accessed 14 Nov 2018

WHO (2018) Health topics: sanitation. https://www.who.int/topics/sanitation/en/. Accessed 17 Mar 2019

Yates T, Allen Vujcic J, Leandre Joseph M et al (2018) Efficacy and effective- ness of water, sanitation, and hygiene interventions in emergencies in low-and middle-income countries: a systematic review. Waterlines 37. https://doi.org/10.3362/1756-3488.17-00016

Zhou F, Xue K, Liu Y et al (2019) Toileting behaviors and factors associated with urinary incontinence in college-aged female students in China. Int Urogynecol J. https://doi.org/10.1007/s00192-019-04043-3

Zomerplaag J, Moojiman A (2005) Child-friendly hygiene and sanitation facilities in schools: indispensable to effective hygiene education. https://www.ircwash.org/sites/default/files/Zomerplaag-2005-Child.pdf. Accessed 10 Mar 2019

Manuscript 1: Supplementary material (as published) (Appendix A5)

Manuscript 1: Supplementary findings (on best practice guidance for the provision of emergency sanitation for children aged five to 11 with UI)

a) Water

Households with children experiencing UI will have additional water supply needs for the increased washing of the child(ren) and laundry (including reusable nappies, clothing and bedding). Children may be involved in the collection of water, although this should not be expected and it should not interfere with education or force the child to walk unreasonable distances or in dangerous places (The Alliance for Child Protection in Humanitarian Action, 2019).

To improve collection:

1. Children's physical abilities, and protection and safety concerns, should be considered when designing water-collection points. This includes, where applicable, the provision of steps with handrails and easy-to-use pumps. Note that children may need to be taught how to use water pumps (and how not to play with water) (Ferron and Lloyd, 2014; The Alliance for Child Protection in Humanitarian Action, 2019); and
2. Although containers specifically made for children are not recommended, the size of water containers provided should be age and size appropriate (The Alliance for Child Protection in Humanitarian Action, 2019). Note that additional water containers may be needed by households with UI children due to additional washing requirements.

b) Sanitation

References to child-friendly latrines/toilets that are applicable to the five to 11 age range were found in the literature (as per 'Manuscript 1'), but there was an absence of specific considerations for children with incontinence with regards to solid waste management.

c) Hygiene: Bathing facilities

Many of the CHILD-SAN considerations as per 'Manuscript 1' are applicable when designing bathing facilities for children aged five to 11, including those with UI. In addition, facilities should allow for the dignified cleaning, drying and disposal of child incontinence materials. Oxfam (2013) also recommends a ratio of two female bathing

facilities to one male, based on the assumption that women tend to bathe children whilst they bathe. This may not be contextually appropriate.

d) Hygiene: Non-food items (NFIs)

Appropriate personal and communal items to support the hygiene, health, dignity and wellbeing of children aged five to 11 (with or without UI) should be available and their use encouraged, noting that if an item or activity is difficult, complex or time-consuming a child may avoid it (UNICEF, 2012). Items can be distributed directly as part of a hygiene kit, or indirectly through the provision of cash, material subsidies and vouchers which offers more flexibility to households (Yates et al., 2017). If directly distributing supplies, some – particularly those related to UI – may need to be distributed discretely to ensure dignity and reduce stigma (Sphere Association, 2018).

Specifically for children aged five to 11, and including those with UI, interventions should provide (Sphere Association, 2018):

- Extra soap (and water). Sphere (2018) recommends 250 grams of soap for bathing per person per month and 200 grams of soap for laundry per person per month, but five times as much water and soap is required for those with incontinence and their carers. Extra soap is therefore recommended (500 grams for bathing and 500 grams for laundry per month);
- Either absorbent soft cotton material (8 square metres per year), disposable incontinence pads (150 per month) or reusable incontinence underwear (12 per year). Different sizes and levels of absorbency should be available;
- Clothing and bedding to maintain health, dignity and wellbeing, including two washable leakproof mattress protectors;
- Bleach or similar disinfectant cleaning product (3 litres of non-diluted product per year);
- Bed pans and urinal bottles (male and female) and/or toilet commode chair (as appropriate), with safe and discrete disposal options available. Such items are particularly applicable for those with social incontinence; and
- Waste disposal mechanisms at home.

Note that proper usage for any unfamiliar items may need to be demonstrated.

Quantitative data was found with regards to the provision of NFIs, which highlighted that indicators are not always being met. For example, in a WASH assessment conducted in 33 (of 34) camps located in Bangladesh's Cox's Bazar District where Rohingya refugees

reside (REACH Initiative, 2018). A household survey was conducted by REACH and other WASH sector partners between August and October 2018. This found that:

- 82% of households reported possession of soap (and this was verified by the enumerator), versus a UNHCR target of more than 90% in the post-emergency phase;
- 27% of households reported facing challenges when accessing soap, with insufficient soap provision in distributions the most cited problem;
- 54% of households reported having never received a full (that is, including non-consumable items, for example water containers) WASH hygiene kit; and
- only 23% of households reported receiving a top-up (that is, including consumables for example soap) WASH hygiene kit within the last month (REACH Initiative, 2018).

Yates et al's systemative review (2018) on the efficacy and effectiveness of short-term WASH interventions in emergency responses in low- and middle-income countries found that standard hygiene kits may not address the needs of larger families or those with different preferences or needs, and that identifying culturally appropriate items was an issue. It concluded that non-functioning markets and procurement delays reduce the overall impact of interventions and for a positive response, pre-positioning of hygiene kits is useful for quick initial distribution followed by a quick release of funds and early triggers for rapid scale-up. Behnke et al. (2018) also concluded that strategic pre-planning results in the most successful responses to displaced persons situations.

UNICEF is the lead agency of the Global WASH Cluster, and its Supply Division is one of many actors that mobilises and distributes supplies in an emergency. The organisation also emphasises emergency preparedness and provides technical guidance to governments to support the advance procurement of the most appropriate items. UNICEF Country Offices can request products from the UNICEF Supply Catalogue, or specific items. The Supply Catalogue includes a few items that could be used to manage UI in children (reusable cloth or menstrual pads washed with laundry detergent would need to be used) but UNICEF is looking to add incontinence-related products to the Catalogue (Shaylor, 2021).

Manuscript 1: Supplementary findings (on the CHILD-SAN sanitation facilities observation checklist)

To support the implementation of CHILD-SAN, an observation checklist was developed for WASH practitioners to use to quickly assess emergency sanitation facilities against the framework (Appendix A6).

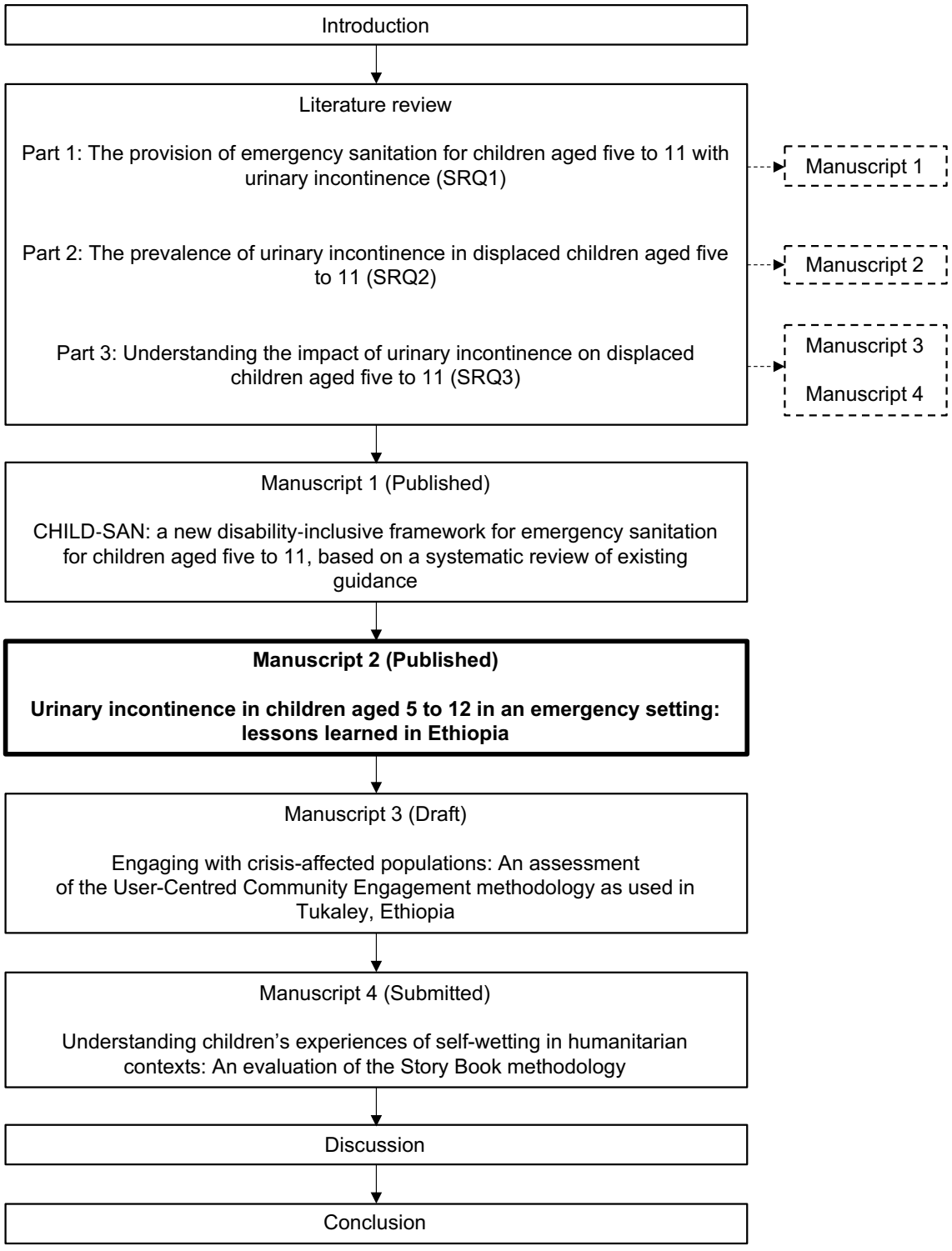
The checklist was trialled in Cox's Bazar refugee camps as part of the project 'Understanding children and their caregivers' experiences with incontinence in humanitarian contexts' (see Part 3 for further details), with 24 checklists completed (Appendix A7). The checklists found that none of the toilets were child-friendly, as for example;

- 46% of toilets (11 of 24) were not located in an appropriate location as per the CHILD-SAN framework;
- 61% of communal toilets (15 of 23) were not gender-segregated (as recommended by the CHILD-SAN framework);
- No signage was provided to any of the communal toilets (well-lit signs using simple communication methods are recommended by the CHILD-SAN framework);
- Only 30% of routes (7 of 23) to the communal sanitation facilities were wide enough for two people or a wheelchair to use (as recommended by the CHILD-SAN framework);
- 68% (15 of 22) of paths to the communal sanitation facilities were found to be difficult for children to walk on;
- None of the toilets had ramps to facilitate access by a wheelchair (the CHILD-SAN framework recommends that ramps are provided to access at least some of the sanitation facilities);
- Over half (52%, 12 of 23 checklists) of the doors did not have locks (the CHILD-SAN framework recommends that doors have locks), albeit all door locks found were in working condition;
- None of the communal toilets had grabrails or handrails (recommended by the CHILD-SAN framework);
- Only 21% (5 of 25) of toilets had a tap or water container in place for handwashing;
- Only 13% (3 of 23) of toilets had soap in place for handwashing; but

- Positively, the average drop hole diameter was 101mm which is smaller than the CHILD-SAN recommended 120mm (to prevent children falling in / being fearful of falling in).

Following the trial, amendments were made to the checklist to facilitate both ease of use, and the quick interpretation of findings to guide action to be taken. This included, for example, clearer wording of questions, and the addition of recommendations as per the CHILD-SAN framework to allow instant comparison with findings as a means to flag the need for action (Appendix A8).

Emergency sanitation for children with urinary incontinence (Rosato-Scott)



Manuscript 2 (Published) (Rosato-Scott et al., 2021b)

Rosato-Scott, C.; Evans, B.E.; Varampath, V.; Fehnert, B. and Barrington, D.J. 2021. Urinary incontinence in children aged 5 to 12 in an emergency setting: lessons learned in Ethiopia. *Waterlines*. **40**(3), pp.179-191

Note: The following version has been amended for the purposes of PhD submission Please see Appendix A9 for the published version.

Note: Please also see 'Literature Review Part 3: Case Study One' for further detail on the User-Centred Community Engagement methodology used in the study on which this manuscript is based.

Abstract

This scoping study aimed to be the first to explore the number of children aged 5 to 12 in an emergency setting (Tukaley village, Ethiopia) wetting themselves, and demand for support to manage self-wetting in the home. A survey asked 524 children about their latrine behaviours; and 312 adult caregivers about the latrine behaviours of the children aged 5 to 12 they care for. Few adult caregivers (1 per cent) indicated that children were self-wetting during the day and/or night, and only one child indicated self-wetting (during the day). Yet the survey revealed demand from adult caregivers for household items typically used to manage involuntary self-wetting. This could suggest self-wetting is occurring, but there is a reluctance to disclose it. Given the impact of self-wetting on the lives of children and their adult caregivers, it would be unethical for it not to be considered when developing emergency programmes across sectors including the water, sanitation, and hygiene sector. With further research and modifications to the survey, it could provide greater clarity on the number of children self-wetting and the scale of demand for support to inform emergency programme design.

Manuscript 2

Urinary incontinence (UI) is the involuntary leakage of urine. Leakage can be continuous or intermittent, and if intermittent can happen at any time, day or night (known as enuresis or bedwetting in children). It is difficult to determine the prevalence of UI in children. Numerous studies have been completed, but comparison is rarely possible due to a lack of homogeneity in study design including definitions, study population, means

of sampling and enrolment, and methods of data collection. As global reference points, Buckley and Lapitan's (2010) review of the best available evidence found that the prevalence of daytime UI in children decreases with age, from 3.2–9.0 per cent in 7-year-olds, to 1.1–12.5 per cent in 11 to 13-year-olds (albeit most studies reported a prevalence of between 1.1 per cent and 4.2 per cent); and the 6th International Consultation on Incontinence found that most studies reported a prevalence of enuresis of 7.0–10.0 per cent at seven years of age, falling to 1.7–4.8 per cent at 11 to 12 years of age (Abrams et al., 2017). Children that wet themselves can experience incontinence-associated dermatitis (similar to nappy rash), skin infections, pressure sores, urinary tract infections, and dehydration (if fluid restriction is used as a management strategy) (Rosato-Scott et al., 2019). The social and emotional impact on their lives and their carers' lives can be significant, and children that wet themselves may also be at risk of abuse from caregivers in response to the leakage (Can et al., 2004; Sapi et al., 2009).

Many studies have investigated the prevalence, management, treatment, and impacts of UI in children in high-income countries (Chang et al., 2017, for example), but less is known about UI in children living in low- and middle-income countries (LMICs) (studies include Sapi et al., 2009; Fockema et al., 2012) and particularly in emergency contexts. For example, at Save the Children at least, incontinence is not included in emergency health data collection templates and would instead be captured in patient notes, yet anecdotally bedwetting is consistently recorded by Child Protection specialists (being a sign of stress and trauma). It is hypothesized that the prevalence of UI in an emergency context will be higher than global estimates for two reasons. First, because of inaccessible and/or inadequate sanitation facilities, a child who has full control of their bladder wets themselves because they do not want/are not able to use the sanitation facilities available – such as communal toilets in a refugee camp (this is known as social urinary incontinence (SUI) (Ryan, 2018)). The second reason is that the child is experiencing stress and trauma. Jurković et al. (2019) identified refugee status as a risk factor in the occurrence of enuresis in children. This is likely due to the cumulative stresses and traumatic experiences of displacement and forced movement, as stress and anxiety have been found to contribute to the causation of enuresis in some children (Nevéus, 2017; Jurković et al., 2019). Although some studies report a higher prevalence of daytime UI in children under stress, the direction of the causal relationship between psychological problems and daytime UI is unclear (Sureshkumar et al., 2000; Buckley and Lapitan, 2010; Abrams et al., 2017). For families with children that wet themselves, managing the condition in an emergency context – whether an established settlement or a camp – could be particularly challenging as required resources may be lacking, including significantly extra water and soap (estimated at five times as much as a person

without incontinence); and time to bathe and wash clothes, bedding, and pads (Sphere Association, 2018). The impacts of the condition may also be far-reaching: embarrassment and shame, or social ostracism (for example, due to smell) could prevent children who wet themselves from participation in programming, education, and social activities (Hafskjold et al., 2016).

Jurković et al. (2019) believe that interest in the connection between enuresis and war stressors is on the rise, originating from Ceri et al.'s (2016) single study group of Yazidi refugee children living in Turkey. Yet a review of the literature did not find a specific study on the prevalence of UI (during the day and/or night) in children aged 5 to 12 (those too old to use small potties, but usually too young to safely and confidently use adult latrines during both the day and night) in an emergency setting, or how best to manage incontinence in children during an emergency. As emergencies progress, the water, sanitation, and hygiene (WASH) sector must move beyond providing initial rapid relief, to 'ensuring conditions that allow people to live with good health, dignity, comfort and safety' (Sphere Association, 2018: 92). Given the impact of UI on the lives of children and their caregivers, it would be unethical for the WASH sector not to consider UI when developing WASH interventions (and preferably with community participation), particularly after the initial stages of an emergency response. Studies that explore UI in children in an emergency context will therefore raise awareness of the condition and support the inclusion of UI on the WASH sector's agenda.

This study aimed to be the first to explore the number of children aged 5 to 12 in an emergency setting wetting themselves, and demand for support to manage self-wetting in the home. The emergency setting was Tukaley in Ethiopia, an established village that hosts an internally displaced person (IDP) population. The study used a survey to ask 1) children aged 5 to 12 about their latrine behaviours; and 2) adult caregivers about the latrine behaviours of the children aged 5 to 12 they care for, as a means to indicate if there were children self-wetting during the day and/or at night. The survey also asked adult caregivers to indicate preferred support options to manage self-wetting in the home.

Materials and methods

The data collection was conducted by Eclipse Experience (Eclipse) and Save the Children (STC, together the Partners) between September 2019 and January 2020 in a protracted emergency setting, Tukaley in Ethiopia. Tukaley is a small *kebele* (village) with a population of 570 households, located north of Kebridahar town in the Korahey

Zone of the Somali Region of Ethiopia. The inhabitants of Tukaley are pastoralist families from various parts of the Somali region, internally displaced since early 2010 due to droughts and large-scale loss of cattle (Bourne and Varampath, 2019). STC constructed the first latrines in Tukaley (four blocks of latrines, each with four cubicles) in 2019, and prior to construction the inhabitants practised open defecation (Bourne and Varampath, 2019). As at September 2019, there were 1,131 children aged 5 to 12 living in Tukaley.

The study used the User-Centred Community Engagement (UCCE) methodology to better understand the latrine behaviours and needs of children aged 5 to 12 in Tukaley (Eclipse Experience, 2019c). During an emergency, community engagement – and particularly with vulnerable populations – is often insufficient or of too low a quality to enable WASH activities to be better designed for the various needs of the community. Rapid needs assessments seldom enable the collection of significant and reliable data and although a lack of time is definitely a constraint, there are also few tools to support data collection and analysis during this time, and those that do exist are not always used. UCCE was designed in response to these challenges. The methodology is composed of several components, the first being an Interactive Digital Survey (IDS) to quickly identify respondents' problem areas related to the latrine and handwashing facilities. Participants in the IDS are either children aged 5 to 12 (child respondents), or adults who care for children aged 5 to 12 (adult caregiver respondents). Once the IDS has been conducted (IDS I), an automatically produced report is reviewed by engineers and priority problems are identified. Co-creation sessions are then held with children and adult caregivers (separately) to explore the problem areas in depth and decide on design changes in a participatory way. The design changes that can be implemented are, and after a period of use a second IDS (IDS 2) is conducted to collect feedback on the altered construction and identify whether there is a need for further alterations (Eclipse Experience, 2019c).

By early 2019, the UCCE methodology had been successfully proved as a concept in Bangladesh (December 2017, an early emergency context) and Iraq (February 2018, a protracted emergency context), and a further study was planned in Ethiopia. It was at this stage that the lead author asked the Partners if they would be willing to amend the surveys used in Bangladesh and Iraq to explore the number of children aged 5 to 12 in an emergency setting wetting themselves, and demand for support to manage self-wetting in the home. Of relevance to this paper:

- The question asked in the Bangladesh and Iraq adult caregiver IDS 'where do your children currently defecate most often?' was split into four to ask where children 1) currently urinate most often during the day; 2) urinate most often during the night; 3) defecate most often during the day; and 4) defecate most

often during the night; and multiple choice answers were expanded to include the home.

- An additional question was added to the adult caregiver IDS, being ‘These are images of three household items: a nappy, a bedpan, and a mattress protector. Please point out any items that would be useful for you and your children’.
- Two additional questions were added to the child IDS, asking ‘where do you currently urinate most often during the day?’ and ‘where do you currently urinate most often during the night?’

The final surveys were translated from English to the local language of the IDPs (Somali) by a member of the STC field team based in Ethiopia. IDS I was conducted in September 2019 by five data collectors who were trained by members of Eclipse. The selection criteria for being asked to take part in IDS I were 1) for adults, to reside in a household with children aged between 5 and 12 years old; and 2) for children, to be aged between 5 and 12 years old. Each data collector was assigned an area of the village and over the course of four days, they called at each household once. The number of surveys completed was limited by the time available, and 524 children and 312 caregivers took part (as some caregivers had multiple children within this age bracket).

This paper has only considered data related to three questions asked in the adult caregiver IDS, and two questions asked in the child IDS:

- Adult caregiver respondents answered the questions ‘where do your children currently urinate most often during the day?’ and ‘where do your children currently urinate most often during the night?’ by tapping once on the appropriate answer text: at home in a bed, at home in a bucket, outside of home around the camp, camp latrines, child-friendly spaces latrines, or other. If other was given as an answer, the data collector asked for more detail and input text to the IDS.
- Adult caregiver respondents also answered the question ‘These are images of three household items: a nappy, a bedpan, and a mattress protector. Please point out any items that would be useful for you and your children’ by tapping on the relevant image(s).
- Child respondents aged 5 to 12 answered the questions ‘where do you currently urinate most often during the day?’ and ‘where do you currently urinate most often during the night?’ by tapping once on an illustration with images depicting home, outside of home around the camp, camp latrines or bush. If home was given as an answer, the data collector asked the respondent ‘Where at home?’, and the respondent answered by tapping once on an illustration with images depicting a child (representing the respondent), a bed, and a bucket.

The anonymous data was stored on a server managed by AidIQ under a subcontract from Eclipse. The lead author viewed the aggregated data on an online hub using a username and password, and the raw data (with individual responses identified by time stamp of survey completion) was also exported in a Microsoft Excel format for analysis. Descriptive statistics were computed to assess the distribution of answers given by adult caregiver respondents and child respondents to 1) where do your children/you currently urinate most often during the day and 2) where do your children/you currently urinate most often during the night; and to assess the distribution of answers given by adult caregiver respondents to the question on household item choices as a means to triangulate the data.

Ethical considerations

The amendments made to the survey for the purpose of exploring the number of children wetting themselves, and demand for support to manage self-wetting in the home were designed to ensure that:

- the primary purpose of the survey (to quickly identify, with minimum intrusion for participants, the most common problem areas children experience during their latrine journey) was not altered;
- there was no mention or suggestion of UI to ensure that such experiences were not interpreted by the survey participants as being problematic, particularly given that support to manage the condition was not being immediately offered.

At each household visited, the data collectors asked the adult residents if there were any children within the target age group (5 to 12 years old) living in the home. If there were any children within the target age group living in the household, the data collector verbally provided information about IDS I (including its purpose and the type of questions that would be asked) to the adult resident, and then asked the adult resident if they would 1) verbally consent to taking part in IDS I, and 2) verbally consent for the children in the household aged between 5 and 12 years old to being asked to assent to take part in IDS I. If the adult resident gave consent to ask the child(ren) aged 5 to 12 in the household to take part in IDS I, the data collector verbally provided child-appropriate information about IDS I to the child(ren) aged 5 to 12 and then asked them individually if they would verbally assent to taking part. Only after verbal consent/assent was obtained was the IDS conducted.

Approval to conduct the Ethiopia study was granted by the STC Deputy Country Director in Ethiopia. The lead author's use of data from the Ethiopia study was approved by the Research Ethics Committee, Faculty of Engineering, University of Leeds, United Kingdom (Reference MEEC 19-018).

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Results

Of the 312 adult caregivers, 223 (71 per cent) reported that their children aged 5 to 12 urinate most often during the day at the camp latrines and 398 (76 per cent) of children aged 5 to 12 reported the same (Table 1). Four caregivers reported that their children aged 5 to 12 urinate most often during the day at home in bed, and two reported urination most often during the day at home in a bucket. Only one child self-reported urinating most often during the day at home, which was in bed.

Table 1 The location of daytime urination of children aged 5 to 12 in Tukaley, Ethiopia

Location[1]	Interactive Digital Survey I respondent group			
	Adult caregivers (responding on behalf of children cared for aged 5 to 12)		Children aged 5 to 12 (self-reporting)	
	(n)	(%)	(n)	(%)
Camp latrines	223	71	398	76
Outside of home, around the camp	67	21	44	8
Bush	Not an answer option[1]		79	15
Child-friendly spaces latrines	12	4	Not an answer option[1]	
At home, in bed	4	1	Not an answer option[1]	
At home, in a bucket	2	1	Not an answer option[1]	
At home	Not an answer option[1]		1	0
Other	4	1	Not an answer option[1]	
Total	**312**	**100**	**522[2]**	**100**

[1]Survey respondents were given different answer options dependent on their respondent group: 1) adult caregivers or 2) children aged 5 to 12.

[2]Two respondents did not answer.

Of the 312 adult caregivers, 204 (65 per cent) reported that their children aged 5 to 12 urinate most often during the night at the camp latrines, and 298 (57 per cent) of children aged 5 to 12 reported the same (Table 2). Of the caregivers, 99 (32 per cent) reported that their children aged 5 to 12 urinate most often during the night outside of home around the camp, and 223 (43 per cent) children aged 5 to 12 also reported urinating most often during the night outside of the home (including in a bush). Three caregivers reported that their children aged 5 to 12 urinate most often during the night at home in bed, and one reported urination most often during the night at home in a bucket. No child self-reported frequent urination at home during the night.

Table 2 The location of nighttime urination of children aged 5 to 12 in Tukaley, Ethiopia

Location[1]	Interactive Digital Survey I respondent group			
	Adult caregivers (responding on behalf of children cared for aged 5 to 12)		Children aged 5 to 12 (self-reporting)	
	(n)	(%)	(n)	(%)
Camp latrines	204	65	298	57
Outside of home, around the camp	99	32	182	35
Bush	Not an answer option[1]		41	8
Child-friendly space latrines	1	0	Not an answer option[1]	
At home, in bed	3	1	Not an answer option[1]	
At home, in a bucket	1	0	Not an answer option[1]	
At home	Not an answer option[1]		0	0
Other	4	1	Not an answer option[1]	
Total	**312**	**100**	**521[2]**	**100**

[1]Survey respondents were given different answer options dependent on their respondent group: 1) adult caregivers or 2) children aged 5 to 12.

[2]Three respondents did not answer.

Of the 312 adult caregivers, 289 (93 per cent) indicated that a bedpan would be useful for them and their children; 73 (23 per cent) selected a nappy; and 59 (19 per cent) chose a mattress protector (Table 3).

Table 3 Household items selected by adult caregivers that would be useful for them and their children

Household item[1]	Adult caregivers	
	(n)	(% of 312 respondents)
Bedpan	289	93
Nappy	73	23
Mattress protector	59	19

[1]Survey respondents could select up to three answers.

Discussion

Of the adult caregivers, 1 per cent (4 of 312) reported that their children aged 5 to 12 urinate most often during the day at home in bed. The number of children to which this relates is unknown: on average adult caregivers reported that three children aged 5 to 12 lived in their household and they may have answered the question thinking about one child in particular, or the children as a group. The age and gender of the children to which these answers relate are therefore also unknown. Only one child of the 522 that completed the IDS self-reported urinating most often during the day at home, which was in bed. The age and gender of the child is unknown as the answer was provided by tapping the screen, and the IDS currently lacks the functionality to report the location of the tap by individual data record (identified by time stamp). Children wetting the bed during the day could have daytime UI, but the results suggest a much lower number of children than global prevalence data indicates: Buckley and Lapitan (2010) found that the prevalence of daytime UI in children decreases with age, from 3.2–9.0 per cent in 7-year-olds, to 1.1–12.5 per cent in 11 to 13-year-olds, albeit most studies reported a prevalence of between 1.1 per cent and 4.2 per cent.

Of the adult caregivers, 1 per cent (3 of 312) reported that their children aged 5 to 12 urinate most often during the night at home in bed, but no child self-reported frequent urination at home during the night. Children wetting the bed at night could have enuresis, but for the same reasons as cited above, prevalence data by age cannot be calculated for this study. Again the results suggest a much lower number of children that could potentially have enuresis than global estimates: the 6th International Consultation on Incontinence found that most studies reported a prevalence of enuresis of 7.0–10.0 per cent at 7 years of age, falling to 1.7–4.8 per cent at 11 to 12 years (Abrams et al., 2017).

Understanding of UI in LMICs, and including emergency settings, is still in its early stages. Previous research conducted in Zambia found a low level of disclosure by adults that they were experiencing incontinence symptoms (that is, self-wetting), with a reluctance to disclose attributed to a lack of awareness that incontinence is a medical condition, and/or the stigma associated with the condition (Rosato-Scott and Barrington, 2018). Interviews with adults and their caregivers revealed this reluctance to disclose rather than an absence of UI, and this is supported by systematic reviews looking at the prevalence of adults experiencing UI in LMICs which find rates in line with global estimates (Walker and Gunasekera, 2011; Rosato-Scott and Barrington, 2018; Mostafaei et al., 2020).

This study assumed that the number of children self-wetting in Tukaley would also be in line with global estimates, or even higher due to the impact of stress and trauma, but this may not hold true. Ashenafi et al. (2001) conducted a survey of mental and behavioural disorders in children aged 5 to 15 years in rural Butajira, a district of southern Ethiopia. The study diagnosed enuresis in 0.8 per cent of the study children (that is, across the age range) through interviews with their caregivers (Ashenafi et al., 2001). Ashenafi et al. (2001) were surprised by their results and concluded that caregivers may not be reporting the condition in children as they do not recognize it (due to, for example, children in rural areas sleeping alone and parents rarely changing children's clothes or making their beds) and children may not be reporting the condition to parents due to the stigma associated with it. Desta et al. (2007) further hypothesized that in rural areas caregivers may not detect bedwetting due to a lack of bedding (commonly children sleep on hay) and the smell of animal excreta masking the smell of human urine (where animals and humans spend the night in the same room).

The prevalence of UI could also be low in Tukaley relative to global estimates. However, when given the choice many adult caregivers selected household items (and some selected multiple household items) that are typically used to manage urinary leakage (bedpans, nappies, and mattress protectors). The selection of nappies (23 per cent, or 73 of 312 caregivers) and mattress protectors (19 per cent, or 59 of 312 caregivers) is indicative of having to manage a problem of involuntary self-wetting. The results of the IDS could therefore indicate a lack of caregiver knowledge about the latrine behaviours of the children they care for and/or a reluctance to disclose. Caregivers may not know where the children they care for usually urinate during the day and night: prior to the installation of latrines in the village open-urination was practised. There may also be a reluctance to report children wetting the bed/self-wetting due to the stigma associated with doing so. Yet 93 per cent (289 of 312) of adult caregivers also selected bedpans. This suggests that a child would voluntarily be able to use it; that is, they are not wetting themselves without control (either during the day or during sleep). This could indicate a reluctance to leave the home to urinate (SUI) rather than having the medical condition of UI. Further, the selection of answers may not actually be related to managing children self-wetting at all: items could have been selected to be used by an adult to manage self-leakage or for completely other purposes, for example to collect rainwater (mattress protector) or store water (bedpan). Without interviews with caregivers and children to interrogate the IDS data, such hypotheses cannot be further explored and it is not possible to determine if the result can be generalized to rural populations of IDPs located elsewhere in Ethiopia and further afield.

Limitations

This was a scoping study to explore the number of children aged 5 to 12 in an emergency setting wetting themselves, and demand for support to manage self-wetting in the home, using a survey-based methodology. Elements of the study design were agreed prior to the lead author's involvement, including location and timing. These factors influenced the number of surveys that were completed, and limited the study to participants who were available at the time of the household visit (and each household was only visited once). This may affect the generalizability of the findings.

Elements of the survey were also agreed prior to the lead author's involvement. This limited the usefulness of the data collected, for example, if caregivers had multiple children aged 5 to 12 it was not possible to know which child(ren) (and their associated demographic data) the survey answers given by the caregivers were referring to.

Finally, the wording of some of the survey questions was not specific enough for the purposes of understanding the support needed in the home to manage self-wetting, notably 'These are images of three household items: a nappy, a bedpan, and a mattress protector. Please point out any items that would be useful for you and your children'. In the absence of interviews with participants it is not possible to interrogate the data to fully understand the true meaning of the answers given.

Conclusions

Four of 312 caregivers reported that their children aged 5 to 12 urinate most often during the day at home in bed (number of children, age, and gender unknown); one child (of 522 that answered the IDS, age and gender unknown) self-reported urinating most often during the day at home in bed; 3 of 312 caregivers reported that their children aged 5 to 12 urinate most often during the night at home in bed (number of children, age, and gender unknown); and not one child (of the 521 that answered the IDS) self-reported urinating most often during the night at home in bed. If it is suggested that children wetting the bed during the day and/or night could have UI, this is an unexpected result relative to global estimates (Buckley and Lapitan, 2010; Abrams et al., 2017).

The number of children self-wetting could be relatively low in Tukaley, but IDS answers indicating demand for nappies and mattress protectors suggests a greater need for support to manage self-wetting than would be expected given the low number of children self-wetting. The results may therefore indicate a reluctance to disclose (by both adult

caregivers and children) due to the stigma associated with incontinence, and the study has identified a further context in which incontinence is a taboo subject. However, a high demand for bedpans was also revealed, which suggests a reluctance to leave the home to urinate (SUI) rather than involuntary leakage (UI). Further, demand for bedpans, nappies, and mattress protectors could be indicative of different problems to be managed, for example, adult self-wetting and/or the need to store water. Without interviews with caregivers and children to interrogate the IDS data such hypotheses cannot be further explored.

Little is known about how displaced children understand and experience health. Migrant research to date has tended to prioritize adult frames of reference, including caregiver's perspectives on children's health-related experiences and needs even though adults do not necessarily make good proxies for children (Curtis et al., 2018; Spencer et al., 2019). The IDS is distinctive in that children themselves participate, and the Ethiopia study was therefore an ideal opportunity to explore the latrine behaviours of the children in greater detail. Amending the questions asked provided deeper insight into how and why the children were using (or not using) the latrines in Tukaley; additional changes (as per 'Final thoughts on future prevalence studies') could provide further understanding about the number of children wetting themselves in an emergency context and the need for support to manage self-wetting without unnecessarily burdening the data collectors (remember that the primary purpose of the IDS is to quickly identify, with minimum intrusion for participants, the most common problem areas children experience during their latrine journey).

Such amendments to the UCCE methodology would be of great use to multiple sectors (including health, protection, children, and WASH) as a means to quickly provide an indication of the numbers of children self-wetting and identify if self-wetting is an issue that requires programmatic support. However, this is reliant on adult caregiver IDS participants being willing to report that the children they care for wet themselves and/or the bed, and child IDS participants self-reporting self-wetting. Where incontinence is a taboo subject, this study suggests that disclosure levels may be low even if support is wanted. The experience of self-wetting can have negative implications for the life of a child medically, socially, and emotionally, and increase the risk of abuse. Support should therefore be provided to manage self-wetting where possible. Research conducted to determine if and how much UI exists in an emergency context may increase awareness across sectors that it should be included on their emergency response agendas, but it should not be necessary to justify providing support for its symptoms where demand is

clearly indicated. The IDS is therefore recommended as a tool to focus on the scale of the support needed, rather than to deeply explore why such support is requested.

Final thoughts on future prevalence studies

- It is unlikely that the medical condition of urinary incontinence could be diagnosed in a humanitarian setting given the burden of data collection on caregivers to provide details of wetting episodes over sustained periods of time. However, further studies could be conducted to provide an indication of the prevalence of self-wetting.
- The IDS used in this scoping study could be amended for such studies to improve the usefulness of the data collected and facilitate analysis. Recommended changes are:
    1. Adult caregivers are asked to disclose the gender and age of the child on which their survey answers are based;
    2. Adult caregiver answer options are amended to more clearly identify self-wetting. Current answer options are at home in a bed, at home in a bucket, outside of home around the camp, camp latrines, child-friendly spaces latrines, or other. The authors suggest that adult caregiver answer options are revised to at home (which if selected triggers further answer options depicted using images of a child, a bed, and a bucket), outside of home around the camp, camp latrines, child-friendly spaces latrines, or other.
    3. Ideally, these answers would be aligned with the children's answer options to allow a quick and easy comparison.
    4. The question on identifying the need for household items could be more clearly worded, for example: 'Please point out any items that would be useful for you and your children to support them urinating and or defecating during the day and/or at night'.
- In totality, these changes should result in a dataset that will provide a clearer indication on the prevalence of self-wetting and the demand for items that can be used to support the management of self-wetting in the home.
- It is also suggested that interviews are held with participants to explore if anything else should be added to the list, for example, additional soap, and how the items identified would be used to support the household.
- Ideally such a study would also incorporate comparable research in a non-emergency context to determine if prevalence rates of self-wetting are impacted by the stress and trauma associated with emergencies.

Final thoughts for the WASH sector

- Families with children that wet themselves will require additional water, soap, and time to bathe and wash clothes, bedding, and pads.
- Camp latrines may never be suitable for all children aged 5 to 12 to use at night (due to, for example, a fear of the dark) and some children may prefer to urinate (and defecate) outside close to home which could be unsafe and unhygienic. The distribution of items to support hygienic urination (and defecation) in the home would discourage open urination (and defecation).
- Surveys to determine the need for household items may not reveal the underlying reason for selection. For example, in this instance it is not known if there is a high demand for bedpans to urinate in, or for an alternative purpose such as to store water. Interviews are therefore recommended to supplement surveys to ensure that the most appropriate household items are distributed.

Manuscript 2: References

Abrams, P., Cardozo, L., Wagg, A., and Wein, A. (eds) (2017) *Incontinence*, 6th edition [online], Bristol: International Continence Society <https://www.ics.org/education/icspublications/icibooks/6thicibook> [accessed 21 November 2018].

Ashenafi, Y., Kebede, D., Desta, M., and Alem, A. (2001) 'Prevalence of mental and behavioural disorders in Ethiopian children', *East African Medical Journal* 78: 308–11 <http://dx.doi.org/10.4314/eamj.v78i6.9024>.

Bourne, S. and Varampath, A. (2019) 'Giving children and caregivers a stronger voice in emergency WASH response' [blog], Reliefweb <https://reliefweb.int/report/ethiopia/giving-children-and-caregivers-stronger-voice-emergency-wash-response> [accessed 14 March 2020].

Buckley, B.S. and Lapitan, M.C.M (2010) 'Prevalence of urinary incontinence in men, women, and children – current evidence: findings of the Fourth International Consultation on Incontinence', *Urology* 76: 265–70 <https://doi.org/10.1016/j.urology.2009.11.078>.

Can, G., Topbas, M., Okten, A., and Kizil, M. (2004) 'Child abuse as a result of enuresis', *Paediatrics International* 46: 64–6 <https://doi.org/10.1111/j.1442-200X.2004.01829.x>.

Ceri, V., Özlü-Erkilic, Z., Özer, Ü., Yalcin, M., Popow, C. and Akkaya-Kalayci, T. (2016) 'Psychiatric symptoms and disorders among Yazidi children and adolescents immediately after forced migration following ISIS attacks', *Neuropsychiatrie* 30: 145–50 <https://doi.org/10.1007/s40211-016-0195-9>.

Chang, S.J., Van Laecke, E., Bauer, S.B., Von Gontard, A., Bagli, D., Bower, W.F., Renson, C., Kawauchi, A., and Shei-Dei Yang, S. (2017) 'Treatment of daytime urinary incontinence: a standardisation document from the International Children's Continence Society', *Neurology and Urodynamics* 36: 43–50 <https://doi.org/10.1002/nau.22911>.

Curtis, P., Thompson, J., and Fairbrother, H. (2018) 'Migrant children within Europe: a systematic review of children's perspectives on their health experiences', *Public Health* 158: 71–85 <https://doi.org/10.1016/j.puhe.2018.01.038>.

Desta, M., Hägglöf, B., Kebede, D. and Alem, A. (2007) 'Socio-demographic and psychopathologic correlates of enuresis in urban Ethiopian children', *Acta Paediatrica* 96: 556–60 <https://doi.org/10.1111/j.1651-2227.2007.00229.x>.

Eclipse Experience (2019) 'User-Centred Community Engagement' [website] <http://www.eclipse-experience.com/user-centred-community-engagement> [accessed 8 March 2019].

Fockema, M.W., Candy, G.P., Kruger, D., and Haffejee, M. (2012) 'Enuresis in South

African children: prevalence, associated factors and parental perception of treatment', *BJU International* 110: 1114–20 <https://doi.org/10.1111/j.1464-410X.2012.11416.x>.

Hafskjold, B., Pop-Stefanija, B., Giles-Hansen, C., Weerts, E., Flynn, E., Wilbur, J., Brogan, K., Ackom, K., Farrington, M., Peuschel, M., Klaesener-Metzner, N., Cordero, R., Cavill, S., and House, S. (2016) 'Taking Stock: Incompetent at incontinence – why are we ignoring the needs of incontinence sufferers?' *Waterlines* 35(3) <http://dx.doi.org/10.3362/1756-3488.2016.018>.

Jurković, M., Tomašković, I., Tomašković, M., Zore, B.S., Pavić, I. and Roić, A.C. (2019) 'Refugee status as a possible risk factor for childhood enuresis', *International Journal of Environmental Research and Public Health* 16(7): 1293 <http://dx.doi.org/10.3390/ijerph16071293>.

Mostafaei, H., Sadeghi-Bazargani, H., Hajebrahimi, S., Salehi-Pourmehr, H., Ghojazadeh, M., Onur, R., Al Mousa, R.T., and Oelke, M. (2020) 'Prevalence of urinary incontinence in the developing world: a systematic review and meta-analysis – a report from the Developing World Committee of the International Continence Society and Iranian Research Center for Evidence Based Medicine', *Neurourology and Urodynamics* 39(4): 1063–86 <http://dx.doi.org/10.1002/nau.24342>.

Nevéus, T. (2017) 'Pathogenesis of enuresis: towards a new understanding', *International Journal of Urology* 24: 174–82 <http://dx.doi.org/10.1111/iju.13310>.

Rosato-Scott, C.A. and Barrington, D.J. (2018) 'Incontinence in Zambia: initial investigation into the coping strategies of sufferers and carers', *Waterlines* 37: 190–206 <http://dx.doi.org/10.3362/1756-3488.18-00012>.

Rosato-Scott, C.A., Giles-Hansen, C., House, S., Wilbur, J., Macauley, M., Barrington, D.J, Culmer, P., and Burke, L. (2019) *Guidance on Supporting People with Incontinence in Humanitarian and Low- and Middle-Income Contexts (LMICs)* [online], University of Leeds <http://dx.doi.org/10.5518/100/13>.

Ryan, F. (2018) '"It's horrifically painful": the disabled women forced into unnecessary surgery', *The Guardian*, 6 August 2018 [online] <https://www.theguardian.com/society/2018/aug/06/disabled-women-surgery-catheter-accessible-toilets> [accessed 27 February 2019].

Sapi, M.C., Vasconcelos, J.S.P., Silva, F.G., Damião, R., and Da Silva, E.A. (2009) 'Assessment of domestic violence against children and adolescents with enuresis', *Jornal de Pediatria* 85: 433–7 <http://dx.doi.org/10.2223/JPED.1935>.

Spencer, G., Smith, M., Thompson, J., Fairbrother, H., Hoare, K., Fouché, C., and Curtis, P. (2019) 'Health experiences of children and young people who migrate: opportunities for health education', *Health Education Journal* 78: 96–107

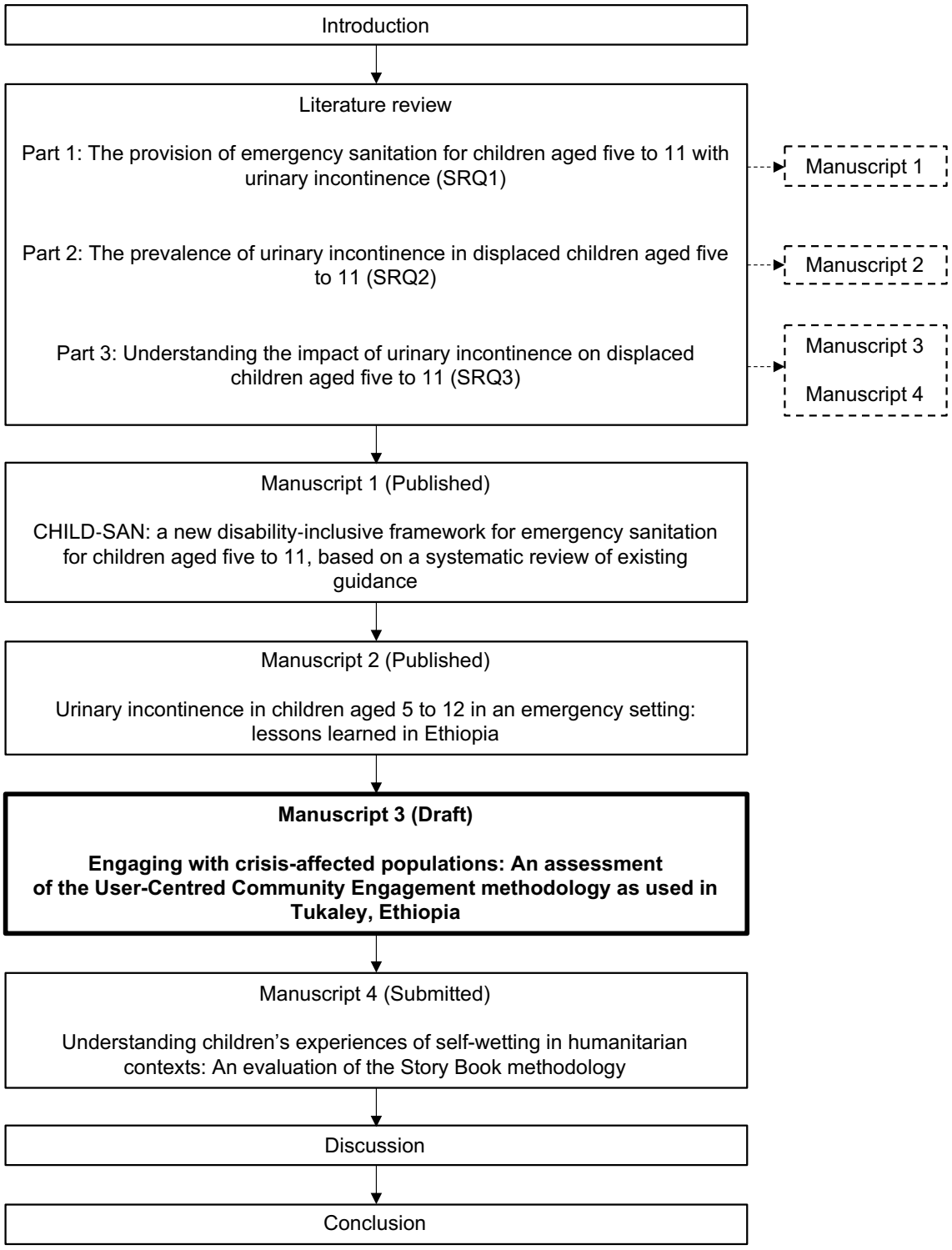
<http://dx.doi.org/10.1177/0017896918786767>.

Sphere Association (2018) *The Sphere Handbook: Humanitarian Charter and Minimum Standards in Humanitarian Response*, 4th edition [online], Geneva, Switzerland: Sphere Association <https://practicalactionpublishing.com/book/2048/the-sphere-handbook> [accessed 21 May 2021].

Sureshkumar, P., Craig, J.C., Roy, L.P. and Knight, J.F. (2000) 'Daytime urinary incontinence in primary school children: a population-based survey', *The Journal of Pediatrics* 137: 814–8 <http://dx.doi.org/10.1067/mpd.2000.109196>.

Walker, G.J.A. and Gunasekera, P. (2011) 'Pelvic organ prolapse and incontinence in developing countries: review of prevalence and risk factors', *International Urogynecological Journal* 22: 127–35 <http://dx.doi.org/10.1007/s00192-010-1215-0>.

Emergency sanitation for children with urinary incontinence (Rosato-Scott)



Manuscript 3 (Draft to be submitted to The Journal of Humanitarian Affairs) (Rosato-Scott and Barrington, tbc)

Rosato-Scott, C. and Barrington, D.J. tbc. Engaging with crisis-affected populations: An assessment of the User-Centred Community Engagement methodology as used in Tukaley, Ethiopia. *Journal of Humanitarian Affairs.* **tbc**

Abstract

Conducting research a) in a humanitarian context and b) with children aged five to 12 presents such unique challenges that those responding to a crisis often design programmes based on their anecdotal experience rather than evidence. The User-Centred Community Engagement (UCCE) methodology was designed by Save the Children and Eclipse Experience to engage with crisis-affected communities to generate practical solutions to their priority needs. Use of the methodology in Tukaley, Ethiopia resulted in daytime usage of the sanitation facilities by children aged five to 12 increasing. This paper has assessed the use of the UCCE methodology in Tukaley. It has found that all elements of the UCCE process were implemented in practice as they were designed to be implemented; both the participants and facilitators found the UCCE methodology acceptable; and the UCCE methodology could be adapted for use in alternative contexts. However, the recruitment and training of facilitators was identified as the biggest challenge faced as the methodology continues on its journey to scale, especially due to the risk that if any component of the UCCE methodology is not done well enough it could damage the willingness of a community to engage in future projects.

Introduction

It is difficult to design and implement evidence-led programmes in response to a humanitarian crisis. Such programmes require the participation of affected populations, but this is not easy in contexts characterised by disruption and instability. These settings present unique challenges to conducting the necessary research, including securing adequate resources (financial, technical, human and time), difficulty in accessing study populations, and the inappropriateness of traditional research methods (Dahab, 2017; Leresche et al., 2020). Conducting research with children in a humanitarian setting presents further challenges due to their particular vulnerabilities, and an emphasis on protecting such children may result in their limited – if at all – participation in the design of humanitarian programmes. As a result, those responding to a crisis tend to design

programmes to meet the immediate needs of the affected population based on their anecdotal experience rather than evidence (Kohrt et al., 2019).

It is hoped that by sharing field experiences on how research has been conducted in humanitarian settings with children aged five to 12, suggestions will emerge on how to address similar challenges faced by researchers. The User-Centred Community Engagement (UCCE) methodology was designed by Save the Children (STC, a child-focused development and humanitarian charity) and Eclipse Experience (Eclipse, a human-centred research and design consultancy) to engage with affected communities – including children aged five to 12 – in order to generate practical solutions to their priority sanitation needs in emergencies which are then acted upon. After successful proofs of concept in Bangladesh (December 2017) and Iraq (February 2018), a further pilot was run in Ethiopia to improve the provision of latrines and handwashing facilities for children aged five to 12 in Tukaley village (Eclipse Experience 2019). This paper assesses the UCCE methodology as used in Tukaley.

An introduction to User-Centred Community Engagement

The UCCE methodology (Figure 1) is comprised of user centred research and design components – each of which has been created specifically to be implemented by local teams.

Figure 5 The UCCE process (Eclipse Experience 2019)

To begin with an Interactive Digital Survey (IDS) is created with local teams as a mechanism to identify the target community's problem areas related to a service or facility. In this instance, an IDS was developed for each of two groups of respondents

(being children aged five to 12; and adult caregivers) to identify problem areas related to the latrine and handwashing facilities. The surveys were designed to be quick, easy-to-use, and engaging for the respondents. Once the surveys have been conducted (IDS 1) an automatically produced report is reviewed by the Project Team and priority problems identified. Co-creation sessions are then held with members of the community to explore the problem areas in depth and for them to suggest potential solutions, in this instance to the design of the latrine and handwashing facilities. The Project Team then follows a decision making process to agree which of the proposed solutions can be implemented. After these changes are made, a further IDS (IDS 2) is conducted to collect feedback on the altered service or facility and identify whether there is a need for further alterations (Eclipse Experience, 2019).

The Ethiopia pilot

The Ethiopia pilot was conducted between September 2019 and January 2020 in Tukaley, a small kebele (village) located north of Kebridahar town in the Korahey Zone of the Somali Region of Ethiopia. As at September 2019, Tukaley had a population of 570 households (including 1,131 children aged five to 12). The inhabitants of Tukaley are pastoralist families from various parts of the Somali region, internally displaced since early 2010 due to droughts and large-scale loss of cattle (Bourne and Varampath, 2019). STC constructed the first latrines in Tukaley (four blocks of latrines, each with four cubicles) in 2019. Prior to construction the inhabitants practiced open defecation (Bourne and Varampath, 2019).

IDS 1 was conducted in September 2019: 524 children (aged between five and 12 years old) and 312 caregivers took part. Three co-creation sessions were also held in September 2019 to discuss the problems identified by IDS 1: one for 30 caregivers (male and female); one for 30 children aged five to eight years old (male and female); and one for 30 children aged nine to 12 years old (male and female). The proposed solutions generated in these sessions were reviewed by members of the Project Team, who decided which changes to implement. The changes made included making the latrine holes smaller (and therefore more suitable for children); repairs to doors, door handles and taps; and the distribution of cleaning kits which included body soap (Eclipse Experience, 2020a). After allowing for a period of use, IDS 2 was conducted in January 2020: 362 children (aged between five and 12 years old) and 318 caregivers took part.

The results of the Ethiopia pilot

The pilot aimed to improve the provision of latrines and handwashing facilities for children aged five to 12 in Tukaley, measured by increased usage. The changes made did increase usage during the day, but not at night:

- In IDS 1, 76% (398) of children reported that they urinated most often during the day in the camp latrines; in IDS 2, 98% (354) of children reported that they urinated most often during the day in the camp latrines.

- In IDS 1, 57% (298) of children reported that they urinated most often during the night in the camp latrines; in IDS 2, 28% (101) of children reported that they urinated most often during the night in the camp latrines. There was no data collected by the IDS which could explain this reduction.

Methods

This paper assesses how the UCCE methodology was implemented in Tukaley. It uses data originally collected for an evaluation of the Ethiopia pilot conducted by researchers at University of Leeds (United Kingdom, UK) and The University of Western Australia. This evaluation specifically aimed to a) understand how the UCCE methodology contributed to the access to and use of sanitation facilities by children aged five to 12 in Tukaley; and b) consider if the pilot achieved its objective of generating and validating the technical specifications of the digital tool and online hub as a means to support bringing UCCE to scale.

The evaluation required an analysis of quantitative data collected by STC during the pilot, and the collection of qualitative data by the lead author. The lead author conducted seven semi-structured interviews with adults known to have participated in the development of the UCCE methodology for the Ethiopia pilot and/or the implementation of the UCCE methodology in Ethiopia (3 Eclipse workers, 2 STC UK workers, 2 STC Ethiopia workers). The interviews were conducted in September and October 2020 remotely (due to COVID-19 restrictions on both travel and face-to-face meetings) using teleconferencing software, and verbal informed consent was obtained from each participant before beginning the interview.

Assessment of the UCCE methodology for this paper

Analysis has been conducted specifically for the purposes of this paper to assess the UCCE methodology using Bowen et al.'s (2010: 3) proposed areas of focus for a feasibility study. This analysis framework was selected as it is designed to determine a) whether a new intervention – such as the UCCE methodology – is appropriate for further testing, and b) if any modifications are needed prior to its further use, as a means to identify those interventions which should be advanced for further testing as they have a high probability of efficacy (Bowen et al. 2010). The framework has been used similarly elsewhere (for example, Weiner et al. 2017 and Zenner et al. 2014).

The de-identified interviews from the original evaluation were uploaded to NVivo 12 for analysis by the lead author. Coding (Table 1) was undertaken using NVivo 12 to analyse the transcripts. The data was first deductively coded using Bowen et al.'s (2010: 3) proposed areas of focus for a feasibility study. Inductive coding was then used within each area of focus to identify themes.

Table 1 Areas of focus adapted from Bowen et al. (2010: 3)

Area of focus	**Definition**
Implementation	How the UCCE methodology was implemented in practice versus how it was designed to be implemented
Practicality	The practical impact of resources (financial, technical, human and time) on the implementation of the UCCE methodology
Acceptability	How acceptable the facilitators and participants found the UCCE methodology
Adaptation	Modifications made to the UCCE methodology due to context

Note that Demand, Expansion, Integration, and Limited-efficacy testing were not deemed to be appropriate areas of focus for this study.

Ethical considerations

Approval to conduct the original evaluation and to publish findings based on the data collected was granted by the Research Ethics Committee, Faculty of Engineering, University of Leeds (Reference MEEC 19-033).

Results

Implementation

All elements of the UCCE process (Figure 1) were implemented in practice as they were designed to be implemented. However, restrictions on project location and timing meant that the Ethiopia pilot was conducted during an ongoing drought in the region. Some Eclipse workers questioned whether the pilot should have been conducted in such circumstances as the community's understandable focus on the lack of water detracted from the needs related to the sanitation facilities that the UCCE methodology was designed to focus on: *'It was middle of the droughts. So of course, the biggest problem was water. And … well, yes, obviously. I'm not sure we needed a survey to find that out'* (Eclipse worker 3). Further, the need to make improvements to training (Figure 1) was also identified (see *Practicality*).

Practicality

Of all of the elements of the UCCE process (Figure 1), the co-creation sessions were most impacted by the challenges of securing adequate resource (in this case, human) to support implementation.

It was often noted that for those not familiar with the UCCE methodology, attention can be mistakenly focused on the IDS as the primary means to engage the community: *'You know sometimes people focus on … the engagement of the surveys themselves … But it's not really about that being gamified that is the true engagement, it's the fact that you're going to do something with that'* (Eclipse worker 1). To do something with the data generated by the interactive surveys (IDS 1), the co-creation sessions are crucial: *'Surveys are easy. They're also not a great research tool, because they're … so constrained. And they don't give you the why, they don't give you … the level of engagement or the level of insight into people's minds'* (Eclipse worker 3).

Although the purpose of the co-creation sessions was well understood, many recognised that doing a co-creation session well – that is, for participants to engage in the session – was challenging and relied on having a suitably skilled and experienced facilitator. Further, it was noted that encouraging participation by children could be more challenging relative to adults: *'It's quite difficult to create an environment where experts don't always give their expert opinion. And … the affected community feels empowered to problem*

solve and come up with ideas' (Eclipse worker 1); *'Getting information out of children is not as easy or not similar to getting information from others'* (STC UK worker 1).

However concerns were raised that the training of the co-creation session facilitators was not sufficient to develop the skills required to engage with children: *'(The) enumerators … were trained largely on the methodology, and the interactive digital tool, which was easy and straightforward, but during the co-creation session, you need to make children speak. And … that's a skill … And that I think, could have been much better'* (STC UK worker 1). It was also felt that more training would be required should the methodology be used again. This was partly a reflection that most of the Data Collectors used in the Ethiopia pilot were no longer employed (high staff turnover is noted as a feature of the humanitarian system): *'(Would you feel confident using the methodology again, without more training?) No, I will need the trainers'* (STC Ethiopia worker 1).

Suitably skilled and experienced facilitators are needed to ensure that the co-creation sessions are meaningful and effective, yet there is a difficulty in either a) recruiting facilitators when needed who are both familiar with the language and culture of the intended participants, and who have the required skills and expertise in engaging with communities and particularly with children; or b) being able to adequately train individuals to be facilitators, and particularly considering that such training ideally would be done remotely: *'Getting the right people for … this … I think that's a … key challenge … If you don't have them in the context then that's that. And … then at the same time, how … far can you get with training people? I don't know. I wonder whether … the soft skills that are needed for facilitation, that you only get with experience to be perfectly honest'* (Eclipse worker 2). Concerns were also raised that without adequate training future pilots could be damaging to both the communities being engaged and the ongoing development of the methodology: *'The whole thing* (training) *can be done remotely, but is quite a lot of work to build out those capabilities and build the confidence in them and also have those evaluated to check that they really work and to understand where people need support and where they … don't … Quality control is a big issue around that as well. Because … to do something badly could have a downside'* (Eclipse worker 1).

Acceptability

Both the participants and facilitators found the UCCE methodology acceptable. NGO workers in Ethiopia reported that the participants were very happy with both the process of the UCCE methodology, and the outcomes: *'The participants were … very happy with the methodology. Because … it was … user-friendly and it was local language that was*

easy to be communicated … The surveys and needs assessments we conducted before were not in that way' (STC Ethiopia worker 2).

The NGO workers also felt that the UCCE methodology was a good methodology. They reported that they were somewhat surprised at the changes proposed by the community as they had perceived the existing sanitation facilities to be of high quality, but they recognised that this was due to both the inclusive nature of the methodology engaging potential latrine users that had previously not been considered (children below the age of ten), and the role of the co-creation sessions in generating solutions to identified problems: *'The methodology…* (It) *widen participation of the community, it engages … different age groups, it is … user-friendly for both caregivers and also for children …* (it) *tries to identify the potential root causes of the problem … And then it also proposes solutions, the solutions came from … the community themselves … So, I think it is the best … methodology'* (STC Ethiopia worker 2).

Adaptation

Respondents felt that the UCCE methodology could be adapted for use in alternative contexts. They felt that they would like to use the UCCE methodology again, in more geographical areas and across different sectors including health, education and nutrition: *'I think it will be good to be used for health and also education projects … as this was good for … sanitation facilities, it will also be applicable to other sectors'* (STC Ethiopia worker 2).

Discussion

The UCCE methodology was designed to support humanitarian practitioners to engage with all members of a community, including children aged five to 12, in the early stages of a humanitarian crisis; provide the affected population with appropriate tools to quickly identify priority problems; facilitate the community to identify potential solutions; and then deliver solutions quickly (Eclipse Experience 2019). In Tukaley, the use of the UCCE methodology resulted in the quick implementation of community-identified solutions which led to daytime usage (albeit not night-time usage) of the sanitation facilities by children aged five to 12 increasing.

Further, this assessment has found that all elements of the UCCE process (Figure 1) were implemented in practice as they were designed to be implemented; both the participants and facilitators found the UCCE methodology acceptable; and the UCCE

methodology could be adapted for use in alternative contexts. However the need to make improvements to training was identified due to the challenges of securing adequate resource (in this case, human) to support the implementation of the co-creation element of the UCCE process (Figure 1).

That the methodology was successful is perhaps a reflection of certain attributes that have been recommended elsewhere to address the challenges of conducting research in humanitarian contexts, namely:

- It is an iterative methodology that produces quick, real-time data;
- It involves the collaboration of an institution experienced in research design and analysis; with a humanitarian organisation that has established local relationships, can help address logistical and security challenges, and can ensure that research findings will benefit the affected populations; and
- It facilitates engagement with affected populations (Kohrt et al., 2019; Shahabuddin et al., 2020; Mistry et al., 2021).

The role of the co-creation sessions in contributing to the success of the methodology will remain key, and this element of the process (Figure 1) was recognised as the most challenging to implement well and particularly with children (O'Kane, 2013). Central to this is the need for an appropriately skilled and experienced facilitator but doubts were raised as to a) how likely it is that appropriately skilled (for example, able to speak the local language and with an understanding of the local context) and experienced (for example, with running group sessions with adults and/or children) would be available where and when needed; and b) how far can the specific skills needed to facilitate a co-creation session be taught in a short amount of time and potentially remotely (O'Kane, 2013)? A further challenge identified was that even if such facilitators can be recruited and trained for a UCCE-based project, staff turnover rates are high in the humanitarian sector and therefore recruitment and training issues may be continually faced.

In response to these challenges, further development of the training provided was identified as being needed. Moving the training online was discussed to increase both the number of people who could access the training and the timescales over which UCCE-specific skills can be learned in preparation for deployment in response to a humanitarian crisis. However, fears were raised that if any component of the UCCE methodology is not done well enough during a project, and particularly the training and co-creation sessions, it could damage the willingness of the community to engage in future projects and also damage the development of the UCCE methodology. Recruiting and training the facilitators needed is therefore the biggest challenge the UCCE

methodology faces as it looks to be used more broadly and to adapt to local needs at scale.

Conclusion

The UCCE methodology was implemented in Tukaley as it was designed to be implemented and both the participants and facilitators found the UCCE methodology acceptable. However, the recruitment and training of facilitators was identified as the key challenge faced by the methodology as it looks to replicate the success of the Ethiopia pilot elsewhere. The UCCE training (along with the UCCE methodology and the UCCE technology) continue to be adapted based on local needs and user feedback, and areas for future pilots to explore include testing the flexibility of the methodology by adapting it for use in new contexts (for example, urban settings and protracted crises); different geographical areas (including South America); and in sectors other than WASH (including education, empowerment and Sexual Reproductive Health).

Manuscript 3: References

Bourne, S. and Varampath, A. (2019) 'Giving children and caregivers a stronger voice in emergency WASH response', *https://reliefweb.int/report/ethiopia/giving-children-and-caregivers-stronger-voice-emergency-wash-response,* (accessed 13 July 2022).

Bowen, D.J., Kreuter, M., Spring, B., Cofta-Woerpel, Ludmila., Linnan, L., Weiner, D., Bakken, S., Kaplan, C.P., Squiers, L., Fabrizio, C. and Fernandez, M. (2010) 'How we design feasibility studies', *American Journal of Preventative Medicine*, 36:5.

Dahab, M. (2017) 'Operational challenges of implementing health research in humanitarian settings. Lessons learned from R2HC funded studies', *www.elrha.org/researchdatabase/operational-challenges-implementing-health-research-humanitarian-settings/,* (accessed 13 July 2022).

Eclipse Experience (2020), 'User-Centred Community Engagement: Ethiopia Pilot Outcomes', *https://static1.squarespace.com/static/5818a9ed2994ca08210fdb36/t/5e58f703086b4403a35fa8e1/1582888711651/UCCE_Ethiopia+Pilot+Outcomes.pdf,* (accessed 13 July 2022).

Eclipse Experience (2019) 'User-Centred Community Engagement', *http://www.eclipse-experience.com/user-centred-community-engagement,* (accessed 16 November 2021).

Kohrt, B.A., Mistry, A.S., Anand, N., Beecroft, B. and Nuwayhid, I. (2019) 'Health research in humanitarian crises: An urgent global imperative', *BMJ Global Health*, 4:6, 1-8.

Leresche, E., Truppa, C., Martin, C., Marnicio, A., Rossi, R., Zmeter, C., Harb, H., Hamadeh, R.S. and Leaning, J. (2020) 'Conducting operational research in humanitarian settings: Is there a shared path for humanitarians, national public health authorities and academics?', *Conflict and Health*, 14:1, 1-14.

Mistry, A.S., Kohrt, B.A., Beecroft, B., Anand, N. and Nuwayhid, I. (2021) 'Introduction to collection: confronting the challenges of health research in humanitarian crises', *Conflict and Health*, 15:1, 1-6.

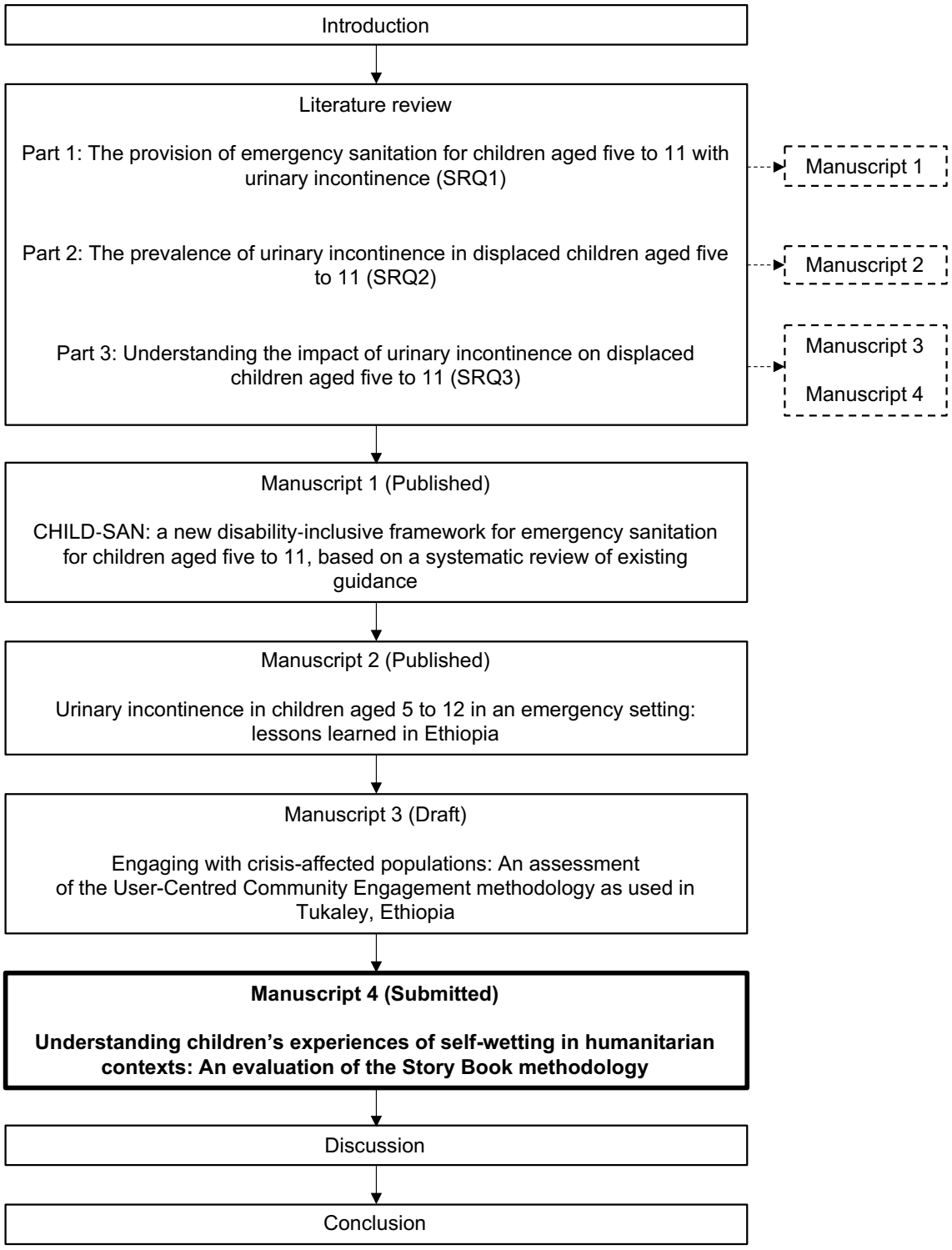
O'Kane, C. (2013), 'Guidelines for Children's Participation in humanitarian programming', *https://resourcecentre.savethechildren.net/document/guidelines-childrens-participation-humanitarian-programming/,* (accessed 11 January 2022).

Shahabuddin, A.S.M., Sharkey, A.B., Jackson, D., Rutter, P., Hasman, A. and Sarker, M. (2020) 'Carrying out embedded implementation research in humanitarian settings: A qualitative study in Cox's Bazar, Bangladesh', *PLoS Medicine*, 17:7, 1-13.

Weiner, B.J., Lewis, C.C., Stanick, C., Powell, B.J., Dorsey, C.N., Clary, A.S., Boynton, M.H. and Halko, H. (2017) 'Psychometric assessment of three newly developed implementation outcome measures', *Implementation Science*, 12:1, 1-12.

Zenner, C., Herrnleben-Kurz, S. and Walach, H. (2014), 'Mindfulness-based interventions in schools – a systematic review and meta-analysis', *Frontiers in Psychology*, 5:603.

Emergency sanitation for children with urinary incontinence (Rosato-Scott)



Manuscript 4 (Submitted) (Rosato-Scott et al., tbc)

Rosato-Scott, C.; Alam, M.; Evans, B.E.; Rose, J.; Wozei, E. and Barrington, D.J. tbc. Understanding children's experiences of self-wetting in humanitarian contexts: An evaluation of the Story Book methodology (Submitted). PLOS Global Public Health. **tbc**

Abstract

Little is known about how children in humanitarian contexts experience self-wetting. Children can wet themselves due to having the medical condition of urinary incontinence (the involuntary leakage of urine), or due to them not wanting to or not being able to use the toilet facilities available (social or functional incontinence). Self-wetting is a global public health challenge: the physical health of children can suffer; they can miss out on educational and social opportunities; they may face increased protection risks; and the emotional effect on daily life can be significantly negative.

The Story Book methodology was developed to facilitate conversations with children aged five to eleven in humanitarian contexts (specifically refugee settlements in Adjumani District, Uganda; and refugee camps in Cox's Bazar, Bangladesh) about self-wetting to understand how humanitarian professionals can best meet the needs of children that wet themselves. This paper has evaluated how far the Story Book methodology meets the specific requirements of conducting research a) in a humanitarian context; b) with young children; and c) on a personal and highly sensitive topic. Data has been used from Story Book sessions held with children in Adjumani District and Cox's Bazar, and from semi-structured interviews held with adults known to have participated in the planning and/or facilitation of the sessions.

The evaluation found that although the Story Book methodology provided deep insights into how children in humanitarian contexts experience self-wetting, it was not always implemented as designed; it is not practical to implement in humanitarian settings; and it was not acceptable to all participants and facilitators as a research tool. Changes have been recommended to improve the methodology as a research tool to better understand how children experience personal health issues, but even with such changes the methodology will remain better suited to non-humanitarian contexts.

Introduction

Background

The Story Book methodology has been developed to facilitate conversations with children aged five to eleven in humanitarian contexts (specifically refugee settlements in Adjumani District, Uganda; and refugee camps in Cox's Bazar, Bangladesh), about a personal and sensitive health issue: self-wetting. Self-wetting is a global public health challenge due to the far-reaching consequences experienced by children who self-wet, yet the experiences of self-wetting children in humanitarian settings have not been explored. The Story Book methodology has therefore been designed to meet the specific requirements of conducting research a) in a humanitarian context; b) with young children; and c) on a highly sensitive topic. This paper is an evaluation of how far the Story Book methodology meets these requirements and can therefore be considered as a research tool for prompting discussions around self-wetting (and sensitive issues more broadly) to support evidence-informed humanitarian programming.

Children's experiences of self-wetting

Children aged between five and eleven years old sometimes wet themselves. This could be due to them having the medical condition of urinary incontinence (UI) defined as the involuntary leakage of urine. Or due to them not wanting to use, or not being able to use, the toilet facilities available (known as social, or functional incontinence).

No matter why a child wets themselves, the consequences are the same. Physical health can suffer; they may experience rashes, urinary tract infections and even dehydration if they restrict liquid intake to reduce the need to urinate (1). They can miss out on educational and social opportunities; they may have increased protection risks due to caregiver frustrations in the home and/or the stigma of incontinence in the community; and the emotional effect of the condition on daily life can be significantly negative (2). Self-wetting is therefore a global public health challenge.

Displaced children's experiences of self-wetting are unknown

The United Nations International Emergency Children's Fund (UNICEF) estimates that 36.5 million children were displaced from their homes at the end of 2021, due to conflict, violence and other crises (3). Little is known about how displaced children understand and experience self-wetting, and how they could be better supported. Spencer et al. (4)

found that there is a “distinct paucity of (migrant) research [on health] that takes children’s perspectives as its starting point” and, to the best of the authors’ knowledge, children in humanitarian contexts have not been spoken to about self-wetting. As a result, humanitarian programmes in sectors including health, protection, and water, sanitation and hygiene (WASH) may not meet the needs of children that wet themselves.

The challenges of conducting research on self-wetting with displaced children

It is difficult to conduct research in a humanitarian setting. Such contexts – at least in the initial stages – are characterised by disruption and instability which present unique challenges to researchers. These include securing adequate resources (financial, technical, human and time), difficulty in accessing study populations, interruptions to public services, and the inappropriateness of traditional research methods (5,6).

Researchers are beginning to share field experiences on how research has been conducted in humanitarian settings (notably 7) and strategies are emerging to address the challenges faced in such a context. These include using flexible, adaptive and iterative methodologies that produce quick, real-time data; collaboration between academic institutions (experienced in research design and analysis) and humanitarian organisations (with established local relationships, to help address logistical and security challenges, and to ensure that research findings will benefit the affected populations) (7–9). Finally and most crucially is the engagement with affected populations to enable trust, improve research design and facilitate the dissemination of findings (7,8).

Conducting research with children in a humanitarian setting presents further challenges. Children are rights-holding individuals and have a right to be heard including in ‘situations of crisis or in its aftermath’ (10,11). Participation has emerged as a concept to describe efforts to implement a child’s right to be heard, and it has been shown that children benefit from being involved in matters that concern them (by, for example, contributing to rehabilitation and strengthening a sense of identity), albeit “care needs to be taken to ensure that participation does not result in exposure to traumatic or harmful situations” (11 Paragraph 125,12).

Professionals in humanitarian contexts aware of the particular vulnerabilities of displaced children may consequently – and understandably – emphasise the protection of children and limit their participation in the design of humanitarian programmes. Guidance has therefore emerged to encourage the inclusion of children in research conducted in humanitarian contexts by outlining ethical principles to adhere to, including beneficence

(promote well-being), non-maleficence (do no harm) and justice (consider who is burdened and who benefits) (13–16).

Finally for consideration are the unique requirements of conducting research on personal and highly sensitive health issues. All known research conducted with adults (none known has been conducted with children) on self-wetting in low- and middle-income contexts has found that there is such a stigma associated with the condition that it is rarely spoken about by those experiencing self-wetting, their caregivers, or the wider community (17–20). It is therefore a topic that is 'best-suited to in-depth discussions, which are flexible in structure and guided by the participant' with measures taken to reduce any embarrassment or discomfort, for example, by using simple language; having discussions in comfortable, private locations; and having men speak with men and women speak with women (21).

The Story Book methodology

In 2019, a Research Team (RT) from University of Leeds (United Kingdom, UK), The University of Western Australia, University of York (UK), Plan International Uganda (PIU), Plan International UK, Uganda Christian University (UCU), UNICEF Bangladesh and World Vision Bangladesh (WVB) was awarded funding from Elhra's Humanitarian Innovation Fund (HIF) for the research project 'Understanding children and their caregivers' experiences with incontinence in humanitarian contexts'.

As – to the best of the authors' knowledge – children in humanitarian contexts had not been spoken to about self-wetting before, the RT, in consultation with an Advisory Board consisting of experts in humanitarian affairs, incontinence and conducting research with children, developed the Story Book methodology. The methodology was developed to facilitate conversations with children aged five to eleven in refugee settlements in Adjumani District, Uganda and refugee camps in Cox's Bazar, Bangladesh about their experiences of this particular health issue. The methodology is a drawing-based research method used in a small group (up to 6 children) setting led by a facilitator. It is designed to address the operational challenges of conducting research in a humanitarian setting (for example, it is implemented through collaboration between academic institutions and humanitarian organisations); the ethical challenges of conducting research with children (for example, by holding discussions within a group context which provides peer support rather than using an interview format); and the specific challenges of conducting research on self-wetting (for example, no participant was asked to share any personal experiences, sharing instead the views of

a ‘hero’ character (Table 1)). For more details on how the methodology was developed see S1 and (16); to view the original study tools see (22).

The RT provided training on the methodology to facilitators in both locations, using a proposed agenda for a 90-minute session (excluding break) (Table 1):

Table 7 Summary of the session guide in which the Story Book methodology was implemented

Agenda item	**Detail**	**Minutes**
Greetings and introduction to the session	The facilitator(s) and observer(s) introduce themselves. The facilitator explains the purpose and structure of the session. The facilitator recaps key assent-related messages including that participants can leave at any time without penalty. Purpose: To ensure that all participants have assented to participation.	5
Ice-breaker	The facilitator chooses an appropriate ice-breaker. Purpose: The ice breaker activity makes children feel more comfortable with each other and with the subject matter of the focus group.	10
Activity 1: Co-creating a hero	The facilitator supports the group to create a main character, or ‘hero’, for their Story Book. The children are asked to choose a gender, age, name, who the hero lives with, the hero’s favourite animal, etc. The facilitator draws the hero as guided by the children. Purpose: As a group, the children create the ‘hero’ for their book. Note that the use of an *imaginary hero* rather than asking participants to share personal experiences of self-wetting reduces the risk of a) a child becoming distressed at being asked to share such experiences and b) a participant being identified by friends, family and the wider community as experiencing self-wetting which may result in negative	5

Agenda item	Detail	Minutes
	consequences due to the stigma associated with the condition.	
Activity 2: Introducing the idea of self-wetting	The children are asked to draw the hero doing their favourite activity, for example playing football, and how they feel doing it. The facilitator then explains that the hero has just wet themselves and asks the children to draw how the hero now feels. At this point the group may discuss reasons why the hero wet themselves. Purpose: As a group, the children begin to explore the feelings of the hero, including when hero has self-wet.	25
Extended snack and play break	To refresh energy levels.	As needed
Activity 3: Exploring a day in the life of the hero	The children are asked to describe what they do as soon as they wake-up. The facilitator then explains that the hero has woken up to find that they have wet the bed and asks the children to draw how the hero feels. The children are then asked to draw how the hero's caregiver reacts to the hero wetting the bed. The facilitator then explains that the hero has now gone to school and wets themself there. The children are asked to draw how the hero feels. The children are then asked to draw how the hero's teacher reacts to the hero wetting themselves at school. At this point the group may discuss ideas for improving the day of the hero. Purpose: As a group, the children continue to explore the hero's feelings and experiences related to self-wetting, and the reactions of friends and community members to better understand the consequences of self-wetting and any stigma associated with self-wetting.	40

Agenda item	Detail	Minutes
Close	The facilitator thanks the children for taking part and explains how their drawings will be used.	5

Methods

Summary

In each location, households with potential participants were identified and consent (from adult caregivers)/assent (from child participants) was sought; to view the forms see (22). Adult caregivers provided written consent where possible. When unable to provide written consent (for example when illiterate), two data collectors witnessed the caregiver's verbal consent on a written consent form. Children provided verbal assent only. Sessions using the Story Book methodology were held in Cox's Bazar in October 2021, and in Adjumani District in February 2022. To evaluate the Story Book methodology, outputs from the session were analysed and semi-structured interviews with adults known to have participated in the planning and/or facilitation of the sessions were also conducted.

Story Book Session: Data collection

In Adjumani District, the sessions were conducted by PIU and UCU in February 2022. Adjumani District is located in northern Uganda and hosts a number of refugee settlements. The majority of refugees are from South Sudan, fleeing a civil war which began in December 2013. Uganda has progressive policies towards refugees relative to neighbouring countries, and refugees have the right to work, the right to the same social services as host communities (health and education for example) and freedom of movement (23). Settlements are therefore long-established and as at 31 January 2022, there were over 244,000 refugees residing in Adjumani District of which 39,000 (16%) were children aged five to eleven (24).

In Cox's Bazar the sessions were conducted by WVB in October 2021. Cox's Bazar is located on the south-eastern coast of Bangladesh, and it is the world's largest refugee settlement. The majority of refugees in Cox's Bazar belong to the Rohingya people, a Muslim ethnic-minority group who have lived for centuries in Myanmar. The Rohingya are not officially recognised as an ethnic group in Myanmar and have faced decades of persecution, forcing many to flee to neighbouring countries including Bangladesh, India and Thailand. In August 2017, violence in Myanmar's Rakhine State triggered the largest

and fastest evacuation: as at 28 February 2022, there were 923,179 Rohingya refugees living in Bangladesh across 34 camps within Cox's Bazar District and on the island of Bhasan Char, of which over 200,000 (22%) were children aged between five and 11 years old (25).

In total, nine sessions were conducted in Adjumani District and eight in Cox's Bazar (Table 2). In Bangladesh the focus group facilitators were hygiene officers used to working with children and known to participants through their ongoing presence in the camp. In Uganda the facilitators were research assistants from the Plan International Uganda database, known to have experience in qualitative data collection and who were familiar with the local community. All facilitators spoke the local languages of the child participants. Sessions were conducted in locations familiar to the children, for example child-friendly spaces, and caregivers were not present (although in Uganda caregivers observed the focus groups from a distance). Children were assigned to focus groups based on their gender, age (5 to 7 years or 8 to 11 years) and residential location only, and had similar socioeconomic and educational status. Participants in a focus group may or may not have known each other prior to taking part in the focus group. Further demographic data on the participants can be found in S2.

Table 8 Story Book session reference by location (see S2 for additional data on sessions held in Cox's Bazar)

Session category (Gender / age in years)	**Adjumani District**			**Cox's Bazar**	
	Ayillo	**Pagirinya**	**Pagirinya host community**	**Camp 7**	**Camp 8E**
Boys / 5 to 7	AD1	AD4	AD8	CB7	CB1
Girls / 5 to 7	AD2	AD5	AD9	CB8	CB3
Boys / 8 to 11	AD3	AD6		CB5	CB4
Girls / 8 to 11		AD7		CB6	CB2
Total by location	**3**	**4**	**2**	**4**	**4**
Total sessions	**17**				

Evaluation of the Story Book methodology

Outputs from all sessions were made available to the RT for analysis via approved and secure platforms and uploaded to NVivo 12 for analysis by the lead author. The outputs analysed were de-identified, translated transcripts of the facilitators describing the

drawings from the sessions held in Adjumani District; de-identified, translated transcripts of the sessions held in Cox's Bazar (these were not available in Adjumani District as the children preferred to draw answers only); photographs of the drawings from all sessions; and facilitator field notes.

The lead author also conducted semi-structured interviews with five adults known to have participated in the planning and/or facilitation of the sessions in Adjumani District or Cox's Bazar (referred to as ADI1; ADI2; ADI3; CBI1; and CBI2). The interviews were conducted in early-2022 remotely using teleconferencing software. Verbal informed consent was obtained from each participant before beginning the interview. De-identified transcripts were stored on an approved and secure platform and uploaded to NVivo 12 for analysis by the lead author.

Coding (Table 3) was undertaken using NVivo 12 to analyse the transcripts (of both the Story Book sessions and semi-structured interviews); drawings; and facilitator fieldnotes. The data was first deductively coded using Bowen et al.'s (26 p.3) proposed areas of focus for a feasibility study, considering that the Story Book methodology was designed to meet the specific requirements of conducting research a) in a humanitarian context; b) with young children; and c) on a highly sensitive topic. This analysis framework was selected as it is designed to determine whether a new intervention – such as the Story Book methodology – is appropriate for further testing and if any modifications are needed prior to its further use, as a means to identify those interventions which should be advanced for further testing as they have a high probability of efficacy (26). Inductive coding was then used within each area of focus to identify themes, and verbal answers given by the children during the sessions in Cox's Bazar were also coded.

Table 9. Areas of focus adapted from Bowen et al.'s (26 p.3).

Area of focus	Definition
Implementation	How the Story Book methodology was implemented in practice versus how it was designed to be implemented (given that it was designed to meet the requirements of a) conducting research in a humanitarian context, b) with young children, on c) a highly sensitive topic)
Practicality	The practical impact of resources (financial, technical, human and time) on the implementation of the Story Book methodology (and therefore how does the methodology meet the requirements of a) conducting research in a humanitarian setting)

Acceptability	How acceptable the child participants found the Story Book methodology (and therefore how does the methodology meet the requirements of conducting research b) with young children on c) a highly sensitive topic)
Adaptation	Modifications made to the Story Book methodology due to context (and therefore how does the methodology adapt to use in a) humanitarian contexts, on c) highly sensitive topics

Note that Demand, Expansion, Integration, and Limited-efficacy testing were not deemed to be appropriate areas of focus for this study.

Ethical considerations

In Adjumani District, households were purposively selected by data collectors familiar with the local communities, being households with children aged five to eleven years old known to experience self-wetting as reported by caregivers. The RT within Uganda (PIU and UCU staff) believed this was the most appropriate way of collecting information on children and caregivers' experiences of self-wetting in this context). In Cox's Bazar, data collectors familiar with the local communities used inclusion criteria – gender (boys and girls); age (five to eleven); living with an adult caregiver – to identify households with potential participants. Purposive selection criteria was not used to identify participants known to experience self-wetting, or be more likely to experience self-wetting (for example, children with a disability), as the RT in Bangladesh (author MUA and WVB staff) felt that the risks of causing personal distress to participants during the Story Book session and/or negative consequences should a child with self-wetting be identified by the wider community, were too high in this context. The RT in Bangladesh concluded that gaining an understanding of the general awareness about and attitudes towards self-wetting, rather than direct personal experiences, was felt to be sufficient to achieve the research objectives whilst protecting the participants from undue harm.

Approval to conduct the project 'Understanding children and their caregivers' experiences with incontinence in humanitarian contexts', including the lead author's evaluation of the Story Book methodology, was granted by the Research Ethics Committee, Faculty of Engineering, University of Leeds, United Kingdom (Reference MEEC 19-020). Approval to conduct the research in Cox's Bazar was granted by the Institutional Review Board of the Institute of Health Economics (University of Dhaka, Bangladesh), with authority to access the refugee camps granted by the Office of the Refugee Relief and Repatriation Commissioner. Approval to conduct the research in

Adjumani District was granted by the UCU Research Ethics Committee (Reference 2021-82) and the Uganda National Council for Science and Technology, with authority to access the refugee settlements granted by The Prime Minister's Office of the Uganda Government.

Results

Implementation

The Story Book methodology was designed to meet the requirements of a) conducting research in a humanitarian context, b) with young children, on c) a highly sensitive topic). However, it was not always implemented as designed (not all activities always took place, most sessions ran over the intended maximum time of 90 minutes, and participants became tired and lost concentration at times), and the data collectors struggled to interpret the data. It therefore did not meet the requirements of conducting research in a humanitarian context (the sessions were too time-intensive and actions to be taken were unclear), and with young children (participants lost interest at times).

The overriding concern of the RT when designing activities for the Story Book session was that the child participants should not experience distress, with measures taken including that they were not to be asked to share personal experiences of self-wetting. In Adjumani District, the children spoke very little during the sessions as 'it was not an easy subject to handle, for the children to open up' (ADI2) so 'those [who] could talk at all, were talking very, very quietly. We could see that it was a struggle to just make them talk because of the experiences I think each one of them has gone through' (ADI1). However, 'you could really see that [the children] are very relaxed' (ADI2). Facilitator field notes in Cox's Bazar reported that 'the children feel free to discuss their incontinence through their drawings as they express it anonymously' although there was one instance of a group being asked to share personal experiences of self-wetting: 'Facilitator: Let me tell you about myself; I felt humiliated … How did you feel then? Child 1: I used to feel ashamed' (CB5). Despite reports that the children were 'happy because for them [the Story Book session] was fun to do' (CBI1), one interviewee on reflection was still concerned that children should not be spoken to about personal health issues as 'it (puts) a kind of fear in them' (CBI2).

The Story Book session was designed to have three activities (Table 1): co-create a hero (Activity 1); introduce the idea of self-wetting (Activity 2); and explore a day in the life of the hero (Activity 3). In Adjumani District workbooks were used with an allocated page for each activity that included a pre-drawn prompt (Activity 1: the outline of a

person and a home; Activity 2: a blank face; Activity 3: a rising sun, a sun, and a moon; see 'Drawing Sheets for Story Book' at (22); and all activities were completed by all FGDs. In Cox's Bazar, all sessions began with Activity 1, but only two (CB6 and CB8) did Activity 2 as designed with all other sessions moving straight to Activity 3 (which eventually CB6 and CB8 did too). The Story Book session guide (Table 1) also suggested that the groups discuss why the hero may self-wet, and ideas for how to improve the day of the hero. These conversations were not held in Adjumani District given the reluctance of the children to speak during the sessions, but it was suggested that 'there … could be two or three questions given to the children to express verbally, maybe at the end of the drawing, they would be in position to talk [as] you could see that they were more willing to open up on the subject' (ADI2). In Cox's Bazar discussions were held in most groups (CB3 and CB4 did not discuss why the hero may self-wet).

The Story Book sessions were designed to be 90 minutes in length, excluding a break between Activities 2 and 3 (Table 1). In Adjumani District the sessions (including breaks) took between 60 and 120 minutes (exact times are not known as the sessions were not audio recorded). Despite concerns noted in some of the transcripts – '[Participant 3] also has the same story with [Participant 2] and I suspect they did not have enough time' (AD1) – those interviewed felt that the sessions were about the right length of time. Story Book sessions in Cox's Bazar (excluding breaks) ranged from 50 minutes (CB3) to 155 minutes (CB5), with an average length of 116 minutes (S2). Interviewees confirmed that a shorter session, as designed, would have been preferred: '(the session) should be within one hour or one hour 30 minutes for both ages … (with a) break after every 30 minutes' (CBI1).

Practicality

The Story Book methodology was designed to meet the requirements of conducting research in a humanitarian context, but it was not found to be practical to implement in humanitarian settings because it is too resource-intensive (in particular, human and time).

Interviewees in Adjumani District raised that 'it would have been much easier if we had been there maybe for a week or two' (ADI2) for the community to feel more comfortable with the researchers, which may have encouraged more verbal discussions during the FGDs. Facilitator field notes stated that 'the activity was very tiresome' but ADI1 commented that 'another thing that worked out very well, those refreshments to make

them relaxed' and 'in fact I think the part where … the children are made to be as relaxed as possible, I think that [should] be emphasised more'. In Cox's Bazar the children became tired and lost concentration at times: 'Do the exercise; they have lost their concentration' (Facilitator, CB5); 'The concentration is lost, they laugh' (Facilitator, CB7). The facilitators did use physical activities such as dancing and snacks to revive energy levels – 'Ok, are you feeling tired? Let's stand if we feel tired, dance a little' (Facilitator, CB2) – but despite such efforts 'going to the end, [the children] feel bored about … doing … more drawings about anything' (CBI2). This impacted participation: 'after a certain period of time, the children has (sic) become so tired and they don't want to do (sic) participate anymore, especially after activity two' (CBI1).

Acceptability

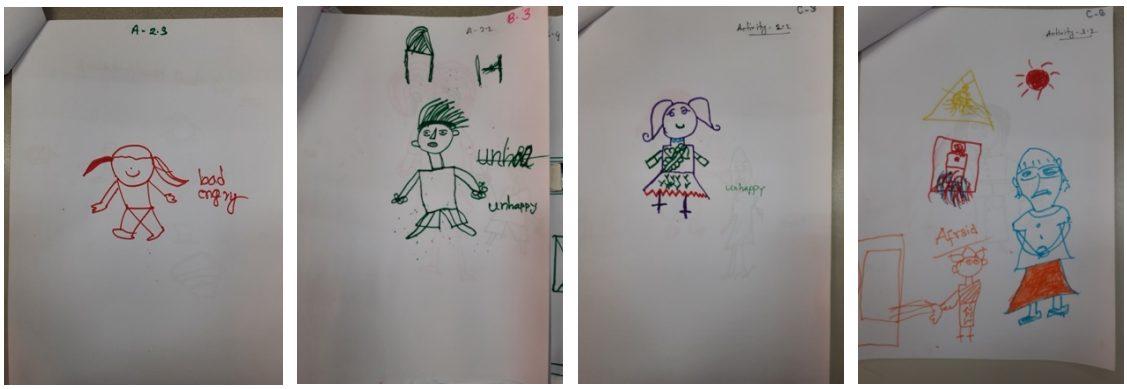
The Story Book methodology was designed to meet the requirements of conducting research with young children on a highly sensitive topic, but it was not always found to be an acceptable method for the facilitators and participants, and particularly for children aged 5 to 7.

An interviewee in Adjumani District reported that 'with the methodology, you could see that … despite the circumstances, the drawing and the Story Book, helped [the children] to open up much more easily than maybe you would have expected' and felt that 'if we're doing real conversation, if we're talking to the children, I think it would have been very complicated … I don't think the children would have [been] happy to talk to us on that subject' (ADI2). As the 'child was asked to imagine it is somebody else made it feel comfortable for the children to respond' so much so that by 'the end of [the session] you could see that [the children] were relaxed and they felt that they had some someone who could talk to them and understand that was not cruel and the subject was not an issue of conflict' (ADI2); 'the children they felt they were being considered' (ADI3). However, despite such positivity it was noted that if purposeful selection criteria had not been used in Adjumani District (and it was not in Cox's Bazar), participants would 'have been more relaxed and more open' (ADI2).

Issues with the activities were noted in Adjumani District, with facilitators noting that 'the baby ones [the 5 to 7 years olds] were unable to shade and even draw the character of the story' (AD Facilitator field notes) and '[the 5 to 7 year old girls] need a lot of patience and guidance on what to do, otherwise they will just colour in a free style' (AD2). Similar issues with the activities were noted in Cox's Bazar with some of the children needing support to think of an answer to the questions being asked: 'the eight to 11 years old

children are quick[er] to grab the question … than the age group of five to seven years old children because it is tough to make them understand the activity' (CBI1). This may have contributed to the facilitator suggesting answers: 'Facilitator 1: She couldn't control her urine, so isn't she feeling bad? Why is she feeling bad? Facilitator 2: Isn't she annoyed because she has no control over herself?' (CB6). Of the 72 answers given to describe how the hero was feeling after self-wetting (at play, home and school), 13 (or 18%) were initially suggested by the facilitator (S2). Of the 62 answers given to describe how friends, caregivers and teachers reacted to the hero after self-wetting, 7 (or 11%) were initially suggested by the facilitator (S2).

Even once a question was understood and a response decided on, some found the concept of drawing emotions too abstract: 'How do I draw these emotions?' (Facilitator, CB5); 'I can't draw like that' (Child, CB5). This resulted in facilitators drawing on behalf of the children at times: 'the early ages children … we have to nudge them, we have to say … You can say to me, I can draw for you. And we did that actually' (CBI2). There was also confusion about what the children were drawing at times: '[Participant 3] I think she was drawing a bed, it is quite strange and not easy to define' (AD2); 'he is saying one thing but has drawn another' (Facilitator, CB1). In Cox's Bazar the names of the emotions that the children were attempting to draw were therefore written onto some of the drawings by either the facilitator or child (Fig 1).



'Bad angry' (CB4) | 'Unhappy' (CB5) | 'Unhappy' (CB8) | 'Afraid' (CB8)

Figure 6 Adding descriptors to explain drawings
Note that the descriptions of the emotion do not clearly match the faces of the drawn figures.

So, whilst 'drawing is the perfect way to understand the incontinence issue of the children, because the children are not comfortable to say this incontinence issue, even to their parents … drawing human figure is tough for them' (CBI1). It was proposed that 'more pictures should appear so that it will be easy for [the children] to give answers' (AD

Facilitator field notes) and/or ‘emojis could be a better options’ (CBI2) which would also ‘reduce the time’ (CBI1) of the FGDs. It was also suggested that a psychologist would have been better placed to facilitate the FGDs and interpret the drawings: ‘we are trying to read their mind but instead of me if there are any psychologist … then they could do it … more clearly’ (CBI2).

Adaptation

The Story Book methodology was designed to be adaptable for use in humanitarian contexts and on highly sensitive topics, but the design was time-intensive and it was not found to have been sufficiently adapted for use in Adjumani District.

An interviewee in Adjumani District noted that ‘the ice breaking parts could be emphasised more to add more of the local content’ (ADI1) with ADI2 suggesting that ‘maybe just adding an aspect of a song, or a story that you know about that imaginary character [about self-wetting] maybe they would have given us more talking’.

Discussion

Lessons learned

The Story Book methodology was used in two very different contexts – refugee settlements in Adjumani District, Uganda and refugee camps in Cox’s Bazar, Bangladesh – but strikingly similar results were found. Participants in both settings showed an awareness that children do wet themselves, and drawings to demonstrate the consequences of this for the child and their caregiver / teacher / friends were largely expressing significantly negative actions and/or emotions (forthcoming manuscripts will provide further details of the specific findings in each context). The Story Book methodology therefore proved – in Adjumani District and Cox’s Bazar at least – that self-wetting is a public health challenge that needs to be on the agenda of humanitarian practitioners. However, this evaluation must conclude that whilst with some amendments the Story Book methodology could be the research tool of choice to prompt discussions with older children on personal and highly sensitive issues, it is unlikely that it could ever be a suitable methodology to be used in a humanitarian setting, or at least in the immediate onset of a crisis.

Reflections on the Story Book methodology as a research tool for a humanitarian context

To be successful in a humanitarian context, a research methodology must be flexible, adaptive and iterative; produce quick, real-time data; and deeply engage with the affected population to enable trust, improve research design and facilitate the dissemination of findings (7–9). The results demonstrate that the Story Book methodology fails to meet these requirements largely because it is so resource-intensive (practicality): context-specific adaptations cannot be done quickly (adaptation); it is dependent on the recruitment and training of data collectors familiar with the local culture and fluent in the languages spoken by participants (practicality); and sufficient engagement with the affected population to build trust with both the participants and wider community takes weeks rather than days (practicality). Further, the data collectors struggled to interpret the data and even then could only hypothesise practical recommendations to improve the wellbeing of displaced children that self-wet (implementation).

Given the resources (financial, technical, human and time) needed to prepare for, conduct and analyse the sessions, the Story Book methodology is therefore better suited as an occasional research tool to determine general needs (most likely at a later stage of an emergency response) rather than as part of an initial needs assessment in an unstable and disrupted environment (27,28).

Reflections on the Story Book methodology as a research tool to facilitate having conversations with children about self-wetting

The RT approached the development of the Story Book methodology from an initial stance of ‘involving children in research is the right thing to do’ and concluded that children should participate because the matter being researched concerned them directly; the RT had the capacity to conduct the research and act on the findings; and the research could be conducted ethically (using the Story Book methodology) (S1 and 16).

This evaluation has found that the Story Book methodology was not always implemented as designed (not all activities always took place, most sessions ran over the intended maximum time of 90 minutes, and participants became tired and lost concentration at times); and not all children found the methodology acceptable (they struggled to provide answers to the questions being asked and to draw a response). Yet the sessions did

provide a safe space for children to do a creative activity that they may not usually do on a daily basis; there were no indications that any child found the sessions to be traumatic or harmful; and the study provided an opportunity – probably for the first time – for children to have their voices heard on a personal and highly sensitive health issue (migrant research to date has tended to prioritise adult frames of reference on children's health-related experiences and needs even though adults do not necessarily make good proxies for children (4,29)).

Recommendations (S3) have been made to improve the implementation and acceptability of the Story Book methodology. If the suggested changes are made, we/the authors believe that the revised Story Book methodology would be a suitable tool to prompt discussions with children aged five to eleven on personal and highly sensitive issues. Where time allows, the methodology could be further adapted to be integrated into a series of activities implemented by teachers (when they have an established and trusting relationship with both the children and caregivers) over several days (or longer). This assumes that the children would be comfortable completing the activities in a school setting, with their teachers, and with known peers, and of course this may not hold true for all participants due to, for example, existing power imbalances between adults and children and/or a shyness to participate around friends (30,31).

Limitations

This research project took place during the COVID-19 outbreak. It had been planned that RT members who developed the Story Book methodology (CRS, JR, DJB) would travel to Bangladesh and Uganda to work directly with PIU and WVB to contextualise the methodology before deployment and adapt it as necessary during data collection. Due to travel restrictions, CRS, JR and DJB were unable to visit Bangladesh or Uganda during the lifetime of the project, so this contextualisation had to take place remotely. After contextualisation, because travel restrictions were still in place, MUA and EW, who were collaborating with the RT on other projects, were invited to partner on this work, training local data collectors and overseeing data collection. However, they had to be trained remotely in the Story Book methodology by CRS and DJB. Due to internet speeds/services and unreliable electricity in Adjumani and Cox's Bazar, online contextualisation and training was difficult and often disjointed. It is likely that if face to face contextualisation and training had been possible, some of the pitfalls of the Story Book approach would have been identified and rectified before implementation.

The number of interviews that could be conducted with adults known to have participated in the planning and/or facilitation of the Story Book sessions was limited by the lead author only being able to conduct research in English. This was mitigated to some degree by the facilitators providing fieldnotes in their preferred language, which were translated to English for analysis.

Conclusion

This paper has evaluated the Story Book methodology as a means to facilitate having conversations with displaced children on highly sensitive topics to inform humanitarian programming. The Story Book sessions held in Adjumani District and Cox's Bazar using the methodology demonstrated that children are aware about self-wetting and tend to associate it with significantly negative emotions and consequences. This justifies considering self-wetting as a public health challenge. However, the Story Book methodology wasn't implemented as designed; it is not easily adapted to, or practical to implement in, humanitarian settings; and it was not acceptable to all participants and facilitators as a research tool to prompt discussions about self-wetting.

Changes have been recommended to improve how the Story Book methodology is implemented in practice and accepted by participants. With such changes it could yet be useful as a research tool to better understand the general needs of children experiencing self-wetting. However, given how resource-intensive the Story Book methodology is, it is unlikely that it could ever be a suitable research tool to be used in a humanitarian setting, or at least in the immediate onset of a crisis.

Manuscript 4: References

1. Great Ormond Street Hospital. Urinary incontinence [Internet]. 2017. Available from: https://www.gosh.nhs.uk/conditions-and-treatments/conditions-we-treat/urinary-incontinence
2. Butler R, Heron J. An exploration of children's views of bed-wetting at 9 years. Child Care Heal Dev. 2007;34(1):65–70.
3. UNICEF. Nearly 37 million children displaced worldwide – highest number ever recorded [Internet]. 2022. Available from: https://www.unicef.org/press-releases/nearly-37-million-children-displaced-worldwide-highest-number-ever-recorded
4. Spencer G, Smith M, Thompson J, Fairbrother H, Hoare K, Fouché C, et al. Health experiences of children and young people who migrate - Opportunities for health education. Health Educ J [Internet]. 2019;78(1):96–107. Available from: https://doi.org/10.1177/0017896918786767
5. Dahab M. Operational challenges of implementing health research in humanitarian settings. Lessons learned from R2HC funded studies. [Internet]. Cardiff: Elrha; 2017. Available from: https://www.elrha.org/researchdatabase/operational-challenges-implementing-health-research-humanitarian-settings/
6. Leresche E, Truppa C, Martin C, Marnicio A, Rossi R, Zmeter C, et al. Conducting operational research in humanitarian settings: Is there a shared path for humanitarians, national public health authorities and academics? Confl Health. 2020;14(1):1–14.
7. Mistry AS, Kohrt BA, Beecroft B, Anand N, Nuwayhid I. Introduction to collection: confronting the challenges of health research in humanitarian crises. Confl Health. 2021;15(1):1–6.
8. Kohrt BA, Mistry AS, Anand N, Beecroft B, Nuwayhid I. Health research in humanitarian crises: An urgent global imperative. BMJ Glob Heal. 2019;4(6):1–8.
9. Shahabuddin ASM, Sharkey AB, Jackson D, Rutter P, Hasman A, Sarker M. Carrying out embedded implementation research in humanitarian settings: A qualitative study in Cox's Bazar, Bangladesh. PLoS Med [Internet]. 2020;17(7):1–13. Available from: http://dx.doi.org/10.1371/journal.pmed.1003148
10. United Nations. The United Nations Convention on the Rights of the Child [Internet]. New York, United States; 1990. Available from: https://www.unicef.org.uk/what-we-do/un-convention-child-rights/
11. United Nations Committee on the Rights of the Child. General Comment No.12.

on the Right of the Child to be Heard [Internet]. Geneva, Switzerland; 2009. Available from: https://www.refworld.org/docid/4ae562c52.html

12. O'Kane C. Review of children's participation in humanitarian programming [Internet]. London, United Kingdom; 2013. Available from: https://resourcecentre.savethechildren.net/document/review-childrens-participation-humanitarian-programming/
13. UNICEF. UNICEF Procedure for Ethical Standards in Research, Evaluation, Data Collection and Analysis [Internet]. 2015. Available from: https://www.unicef.org/media/54796/file
14. Berman G, Hart J, O'Mathúna D, Mattellone E, Potts A, O'Kane C, et al. What We Know about Ethical Research Involving Children in Humanitarian Settings An overview of principles, the literature and case studies, Innocenti Working Paper No. 2016-18 [Internet]. Florence, Italy; 2016. Available from: https://www.unicef-irc.org/publications/849-what-we-know-about-ethical-research-involving-children-in-humanitarian-settings-an.html
15. Maglio F, Pherali T. Ethical reflections on children's participation in educational research during humanitarian crises. Res Ethics. 2020;16(1–2):1–19.
16. Rosato-Scott C. Emergency sanitation for children with urinary incontinence [Forthcoming]. PhD thesis. University of Leeds; 2023.
17. Rosato-Scott CA, Barrington DJ. Incontinence in Zambia: initial investigation into the coping strategies of sufferers and carers. Waterlines [Internet]. 2018;37(3):190–206. Available from: http://dx.doi.org/10.3362/1756-3488.18-00012
18. Bhakta A, Esseku H, Esseku Y, Fisher J, Reed B. The hidden wash needs of perimenopausal women. J Water Sanit Hyg Dev. 2021;11(6):1016–25.
19. Wilbur J, Morrison C, Bambery L, Tanguay J, Baker S, Sheppard P, et al. "I'm scared to talk about it": exploring experiences of incontinence for people with and without disabilities in Vanuatu, using mixed methods. Lancet Reg Heal - West Pacific [Internet]. 2021;14:100237. Available from: https://doi.org/10.1016/j.lanwpc.2021.100237
20. Ansari Z, White S. Managing incontinence in low-and middle income-countries : A qualitative case study. PLoS One. 2022;17(7):1–16.
21. Rosato-Scott C, Barrington DJ, Bhakta AN, House S, Mactaggart I, Wilbur J. Incontinence: We Need to Talk About Leaks [Internet]. Brighton: IDS; 2020. Available from: https://doi.10.19088/SLH.2020.005
22. Barrington DJ. Understanding children and their caregivers' experiences with incontinence in humanitarian contexts [Internet]. 2022. Available from: https://osf.io/e3khv/

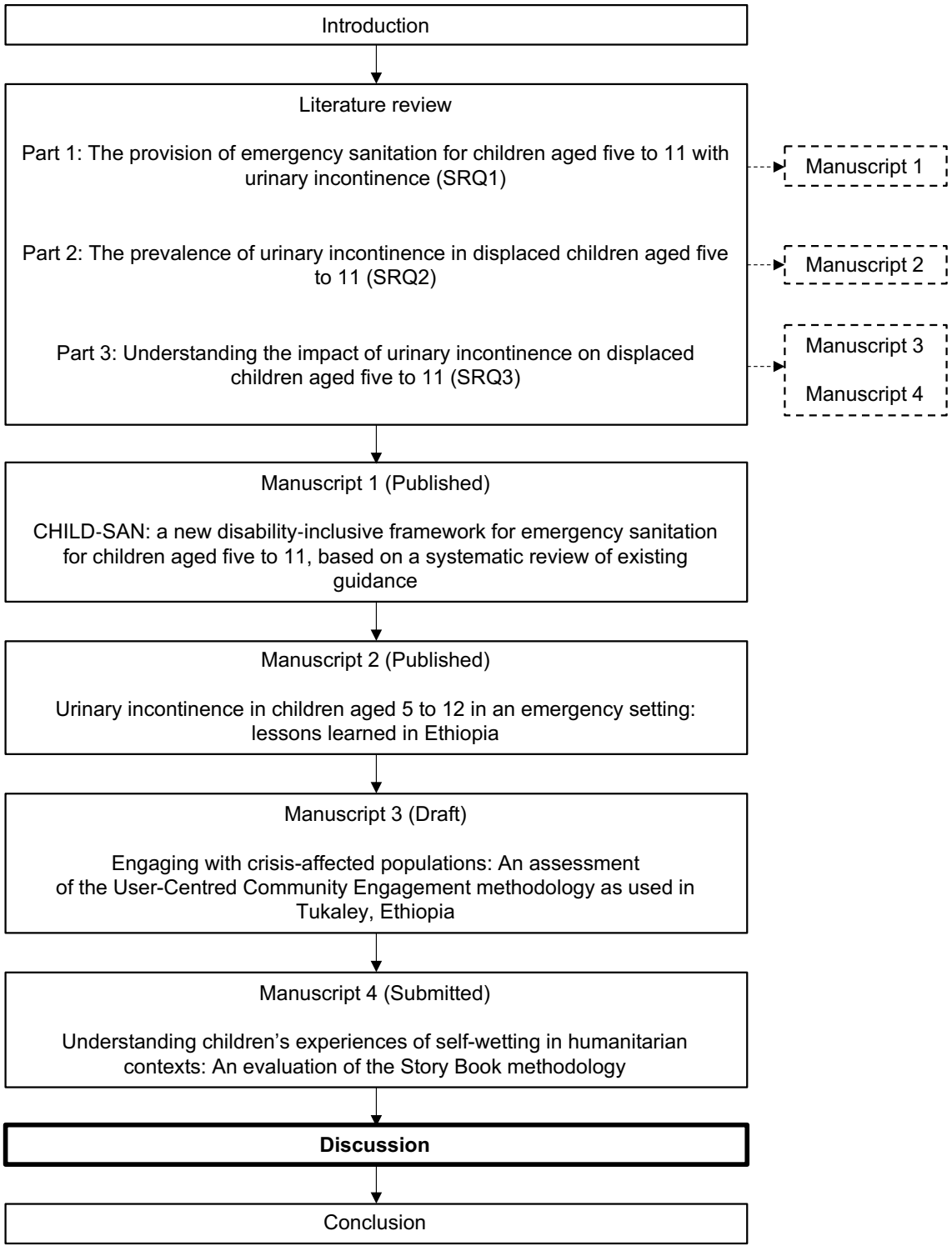
23. Easton-Calabria E. Uganda has a remarkable history of hosting refugees, but its efforts are underfunded [Internet]. The Conversation. 2021. Available from: https://theconversation.com/uganda-has-a-remarkable-history-of-hosting-refugees-but-its-efforts-are-underfunded-166706
24. UNHCR. Uganda - Refugee Statistics January 2022 - Adjumani [Internet]. 2022. Available from: https://data2.unhcr.org/en/documents/details/91063#_ga=2.208232017.259918307.1646837854-139497318.1646837854
25. Government of Bangladesh, UNHCR. Joint Government of Bangladesh - UNHCR Population factsheet as of 28 February 2022 [Internet]. 2022. Available from: https://data2.unhcr.org/en/documents/details/91302
26. Bowen DJ, Kreuter M, Spring B, Linnan L, Weiner D, Bakken S, et al. NIH Public Access: how to design feasibility study. Am J Prev Med. 2010;36(5):452–7.
27. Yates T, Allen Vujcic J, Leandre Joseph M, Gallandat K, Lantagne D. Efficacy and effectiveness of water, sanitation, and hygiene interventions in emergencies in low-and middle-income countries: a systematic review. Waterlines [Internet]. 2018;37(1). Available from: http://dx.doi.org/10.3362/1756-3488.17-00016,ISSN:0262-8104
28. WHO. Managing WHO Humanitarian Response in the Field [Internet]. Geneva, Switzerland; 2008. Available from: https://www.who.int/publications-detail-redirect/managing-who-humanitarian-response-in-the-field
29. Curtis P, Thompson J, Fairbrother H. Migrant children within Europe: a systematic review of children's perspectives on their health experiences. Public Health [Internet]. 2018;158:71–85. Available from: https://doi.org/10.1016/j.puhe.2018.01.038
30. Morgan M, Gibbs S, Maxwell K, Britten N. Hearing children's voices: methodological issues in conducting focus groups with children aged 7–11 years. Qual Res. 2002;2(1):5–20.
31. Noble-Carr D. Engaging Children in Research on Sensitive Issues. 2006.

Manuscript 4: S1 Supporting Information: Extracts from the PhD thesis of C. Rosato-Scott detailing development of the Story Book Methodology (Appendix A10)

Manuscript 4: S2 Supporting Information: Data on sessions held in Cox's Bazar (Appendix A11)

Manuscript 4: S3 Supporting Information: Recommendations (Appendix A12)

Emergency sanitation for children with urinary incontinence (Rosato-Scott)



Discussion

Urinary incontinence versus self-wetting in displaced children aged five to 11

The PRQ of this PhD is 'how is UI in children aged five to 11 best understood and managed during an emergency'. To begin answering this PRQ, we must first revisit what UI is in displaced children aged five to 11. To describe a child as being urinary incontinent implies that they have a medical condition; the involuntary loss of urine. There are strict criteria to be met for a child to be diagnosed as having UI during the day (daytime urinary incontinence, DUI) and/or at night (enuresis or bedwetting) which include a minimum age (of five years old) and leakage frequency (American Psychiatric Association, 2013; Austin et al., 2016; WHO 2018). Yet a child may also urinate on themselves due to not wanting to use, or not being able to use, the sanitation facilities available: this has been termed 'social incontinence' and it is not a medical condition (Ryan, 2018).

In an emergency context, it is likely that there will be children with the medical condition of UI, and children who are urinating on themselves due to having social incontinence. It may not always be clear why a child is urinating on themselves, even to their caregiver. It is also unlikely that in such a context healthcare would be available for a caregiver to seek a diagnosis should they wish to do so (and medical help is not often sought by caregivers of children who urinate on themselves) (see Esezobor et al., 2015 for example). Further, research has found that urination on the self has a significantly negative impact on the quality of life of the children that experience the condition, and those that care for them, regardless of the causation (Rosato-Scott et al., tbc). This PhD has therefore used the term 'self-wetting' to describe children who are urinating on themselves when the cause of the self-wetting is unknown, and has sought to consider how is self-wetting (rather than only UI) in children aged five to 11 best understood and managed during an emergency.

The prevalence of self-wetting in displaced children aged five to 11

It is hard to know how many children wet themselves, either due to them having the medical condition of UI; or due to them not wanting to use, or not being able to use, the toilet facilities available (social incontinence). Numerous studies have been completed but comparison is rarely possible due to variances in definitions and methodologies. In non-emergency contexts it can be assumed that 2.0-9.0% of children aged five to 11 wet themselves during the day, and 5.0-20.0% of the same age group wet themselves at

night (bed-wetting or enuresis) due to experiencing the medical condition of UI (Morison et al., 2004; Buckley and Lapitan, 2010; Abrams et al., 2017).

It was hypothesised that more children will wet themselves (during the day and/or at night) in an emergency context relative to a non-emergency context: refugee status has been identified as a risk factor in the occurrence of enuresis; stress and anxiety have been found to contribute to the causation of primary enuresis (enuresis without a previous dry period); exposure to stressful events or life changes increases the risk of secondary enuresis (enuresis following a dry period of more than six months, although this association may be bidirectional); and children do not like to use sanitation facilities that are difficult to access and/or use (Keith, 1968; Järvelin et al., 1990; Joinson et al., 2016; Jurković et al., 2019; Eclipse Experience, 2020). However, a survey completed by children aged five to 12 and their caregivers in Tukaley (Ethiopia) indicated lower prevalence rates relative to global, non-emergency context (baseline) estimates (Rosato-Scott et al., 2021b).

The scoping study completed in Tukaley aimed to be the first to explore the number of children aged 5 to 12 in an emergency setting wetting themselves, and demand for support to manage self-wetting in the home. A survey asked 524 children about their latrine behaviours; and 312 adult caregivers about the latrine behaviours of the children aged 5 to 12 they care for. Few adult caregivers (1 per cent) indicated that children were self-wetting during the day and/or night, and only one child indicated self-wetting (during the day).

The results of the study were unexpected (relative to baseline estimates; and versus the hypothesis that the prevalence rates of children experiencing UI in emergency settings would be higher than baseline estimates). It could simply be that few children in Tukaley experience self-wetting. However, the survey also revealed demand from adult caregivers for household items typically used to manage involuntary self-wetting (nappies and mattress protectors) and self-wetting due to a reluctance to use the sanitation facilities available (nappies and bedpans). This could suggest children are self-wetting, but there is a reluctance to disclose it; or an adult needs the products to manage self-leakage; or the products are needed for other purposes such as collecting rainwater (mattress protector) and storing water (bedpan). Without interviews with caregivers and children to interrogate the survey data, such hypotheses cannot be further explored.

It can therefore be concluded from the scoping study conducted in Tukaley that a) the focus of research on self-wetting in humanitarian contexts should not be on prevalence (noting that previous research conducted by Rosato-Scott and Barrington (2018) in Zambia revealed a reluctance to disclose rather than an absence of UI); and b) if there is self-wetting occurring in a household then qualitative approaches are needed to fully understand the experiences of self-wetting by displaced children and their caregivers.

The need for evidence-led emergency programmes to support displaced children aged five to 11 that self-wet

Given the broad impact of self-wetting on the physical health, and social and emotional wellbeing of both the child self-wetting and their caregivers, many sectors could provide support in an emergency setting (Rosato-Scott et al., 2020). These include health (including nutrition and occupational therapists); protection; gender-based violence; disability; children; gender; livelihoods; and WASH. Kohrt et al., (2019) found that those responding to a crisis focus (usually) limited resources on the immediate needs of the affected population, designing programmes based on anecdotal experience rather than being evidence-led. These may not always meet the needs of the affected community.

Conducting qualitative research to better understand the experiences of displaced children that are self-wetting would therefore support emergency programmes to better address the needs of such children and their caregivers. Reasons to do so include the potential vast number of beneficiaries (even in the absence of self-disclosure); that children have a right to sanitation (which the international community via SDG 6 is aiming to achieve by 2030); and that displaced children should be supported to live with good health (in the broadest sense of physical, mental and social well-being), dignity, comfort and safety (WHO, 2006; United Nations, 2015; United Nations, 2016; Sphere Association, 2018).

How to better understand self-wetting in displaced children aged five to 11

Little is known about how displaced children understand and experience health: migrant research to date has tended to prioritize adult frames of reference, including caregiver's perspectives on children's health-related experiences and needs even though adults do not necessarily make good proxies for children (Curtis et al., 2018; Spencer et al., 2019). Reasons for this include that it is difficult to conduct research in a humanitarian setting, and conducting research with children in a humanitarian setting – particularly on a sensitive personal issues – presents further challenges. This PhD has evaluated two

research methodologies that have been specifically designed to address the challenges of conducting research with displaced children on sensitive personal issues: the UCCE methodology and the Story Book methodology.

A summary of the objectives of the two research methods

Both the UCCE and Story Book methodologies aimed to facilitate the participation of children aged five to 11 (Story Book) /12 (UCCE) in the design of evidence-led humanitarian programmes. The UCCE methodology aimed to improve the provision of latrines and hand-washing facilities for children aged five to 12, by a) identifying the priority issues and then b) co-creating solutions to the identified priority issues, which were then implemented as far as possible. The Story Book methodology is a phenomenological approach which aimed to understand the lived experiences of children aged five to 11 that self-wet as a first-step in thinking about how humanitarian programmes across sectors including health, protection and WASH can better meet the needs of self-wetting children.

Recommendations have been made to improve the implementation of the UCCE methodology (Rosato-Scott et al., 2021b) and the Story Book methodology (S2 Supporting Information of Rosato-Scott et al., tbc). With such changes, the UCCE methodology could provide more insight on the number of children self-wetting, and the Story Book methodology could better generate practical suggestions on how to improve the lives of children who self-wet.

Reflections on the findings of the methodologies regarding displaced children self-wetting

The UCCE methodology indicated that children do not always use the sanitation facilities available (particularly when user satisfaction with the facilities is low) and may therefore urinate and/or defecate elsewhere (Rosato-Scott et al., 2021b). This can put children – and particularly girls – at risk of injury or abuse (Oxfam International and WEDC. 2018). Results did not directly indicate that children are urinating and/or defecating on themselves instead of using the sanitation facilities provided, but this could be due to a reluctance to disclose due to stigma associated with self-wetting (as noted elsewhere, for example Rosato-Scott and Barrington 2018).

The Story Book methodology provided a deeper level of insight into the impact of self-wetting on displaced children aged five to 11 than a survey can achieve, in a more

considered way than by interviewing children. Use of the methodology in two very different contexts – refugee settlements in Adjumani District, Uganda and Cox's Bazar refugee camps in Bangladesh – found that there is a stigma associated with self-wetting; and that self-wetting can have a significantly negative impact on the quality of life of the children that experience the condition, and those that care for the children that self-wet (Rosato-Scott et al., tbc).

Results from Adjumani District, Cox's Bazar and Tukaley were similar in that they acknowledged that children can self-wet due to not wanting to use, or not being able to use, the sanitation facilities available. It would therefore be reasonable to assume that there will be children in all humanitarian contexts that do not want, or are not able, to use the sanitation facilities available. Results from all three settings also suggested a level of stigma associated with self-wetting, and again it would be reasonable to assume that this will always be the case (as per research conducted across multiple and diverse low- and middle-income contexts (Rosato-Scott et al., 2020)).

The consequences of such a stigma (particularly on the social and emotional well-being of both the children self-wetting and their caregivers) were noted as being similarly negative in both Adjumani District and Cox's Bazar. Such consequences were not dissimilar to research conducted elsewhere in low- and middle-income contexts, particularly with respect to the social isolation and violence (verbal and physical) experienced by the children and so once more it would be reasonable to assume that this could occur elsewhere (Rosato-Scott et al., 2020). The surveys conducted in Tukaley were unable to provide insight on the consequences of self-wetting for both the children and their caregivers.

Reflections on the methodologies as a means to engage with displaced children aged five to 11

The Interactive Digital Survey (IDS) used in the UCCE methodology was quick, easy and engaging for the children to use. It is a flexible, adaptive and iterative methodology that produces quick, real-time, actionable data and as such addresses many of the operational challenges of conducting research in humanitarian contexts (Kohrt et al., 2019; Shahabuddin et al., 2020; Mistry et al., 2021). With minimal investment of resources it could be adapted to be used by different sectors and in different contexts, with minimal training needed for data collectors and data analysts. Over time a library of surveys could be generated, the hope being that eventually a version would be available for any context that would require very little adaptation allowing for more rapid

implementation in the field. However, the IDS will never be able to explain the 'why' behind the issues and/or wants (if an IDS is adapted to include such questions) identified. This cannot be achieved without conversations with the affected population.

The co-creation sessions used in the UCCE methodology and the focus groups used in the Story Book methodology were designed to facilitate having such conversations with the affected population. They both provide – probably unprecedented – opportunities for children aged five to 11/12 to have their voices heard, and to truly participate in the design of evidence-led humanitarian programmes. To recap, the benefits of that can include "helping children to regain control over their lives, contributing to rehabilitation, developing organisational skills and strengthening a sense of identity" (United Nations Committee on the Rights of the Child 2009 Paragraph 125). They also both generate insight that humanitarian practitioners can use to better understand how to meet the needs of communities in crisis.

However, they are resource-intensive methodologies (in particular, time and people) that rely on group facilitators familiar with the local context, fluent in the languages spoken by the affected populations, and trained in the research approach. Further, results from research conducted in one location could not be said with certainty to be applicable elsewhere. As such, they will always require some adaptation before use; they will always require investment in the recruitment and training of facilitators before implementation; and they will work best when sufficient time is allowed to establish trust between the researchers and the community (being weeks rather than days). None of this is without its challenges (O'Kane 2013).

How is social incontinence in displaced children aged five to 11 best managed?

When children are self-wetting because they do not want to, or are not able to, use the sanitation facilities available, improving the sanitation facilities is the most likely means to improve the quality of life for these children and their caregivers.

A systematic literature review found largely anecdotal evidence on the provision and use of emergency WASH facilities, resources and services by children aged five to 11, with nothing specifically mentioned regarding children of that age group that self-wet (Rosato-Scott et al., 2021a). The review found that emergency sanitation facilities are rarely designed with consideration of children aged five to 11, or even later adapted for children of this age group to use (later confirmed by research conducted in refugee camps in Cox's Bazar for the purposes of this PhD: see Manuscript 1 Supplementary findings on

the CHILD-SAN sanitation facilities observation checklist), although examples of this can be found (notably Eclipse Experience, 2019). This is despite there being best practice guidance available. As a result, children can struggle, or even refuse, to use emergency sanitation facilities designed for adults. This may result in social incontinence.

The author developed the CHILD-SAN framework (and associated Observation Checklist) to support the WASH sector to better provide sanitation facilities for children (Rosato-Scott et al., 2021a). Based on a systematic literature review of existing guidance, CHILD-SAN is a disability-inclusive framework that recommends (a) safe and meaningful child participation in emergency WASH preparedness planning and emergency WASH programming as a means to develop contextually appropriate facilities, (b) specific design considerations for child-friendly toilets and (c) the collection of sex-, age- and disability-disaggregated data against contextually appropriate indicators to determine the prevalence of child-friendly facilities and their use. It is hoped that by providing sanitation facilities that adhere to the recommendations of the CHILD-SAN framework, children will want to use them, and will be able to use them. This would reduce instances of social incontinence and the associated negative consequences for both the children and their caregivers, improving their quality of life.

Using the UCCE methodology to improve the quality of life of children with social incontinence

The IDS of the UCCE methodology is a needs assessment tool that compared to traditional tools is quicker for an enumerator to both collect and analyse data; and which facilitates the direct participation of children in a fun and engaging way. Used in isolation (without the co-creation sessions), this would at least guide practitioners on where to focus efforts to improve, in this instance, sanitation facilities.

In its current iteration, for the IDS to be successful it requires an existing service provision. That is, it identifies wants/needs for improvement rather than wants/needs where no service is currently available (although it could possibly be adapted to do so). In the early stages of a humanitarian response it could therefore be challenging to use an IDS as the graphics would need to reflect the rapidly changing current situation. Once more stable facilities have been installed however, the IDS could be used to identify where improvements could be made. Further, the results of all IDS's completed could be used to strengthen the CHILD-SAN framework on which the initial provision of facilities would (ideally) be based.

The co-creation sessions of the UCCE methodology provide a further opportunity for the children to participate in the improvement of existing sanitation facilities, and allow for a more in-depth exploration of the issues experienced and potential solutions to them. When resources allow, the (full) UCCE methodology would therefore be useful to facilitate children aged five to 12 to participate in the design of evidence-led humanitarian programmes.

How is UI in displaced children aged five to 11 best managed?

In a non-emergency context, a child diagnosed with UI would hopefully have access to urotherapy treatment, which would most likely begin with demystification of the condition, followed by the treatment of any constipation, and then with simple lifestyle and behavioural interventions which require the limited involvement of healthcare professionals (Buckley et al., 2019). If this is not successful, treatment can progress to pharmacological and/or surgical interventions. Unfortunately, the diagnosis of UI and the subsequent provision of medicalised support remains unlikely in a humanitarian context. Instead, attention tends to be focused in the first instance on how the WASH sector can support children that are self-wetting given that they have significantly increased needs for water supply and for accessible, private WASH facilities (Rosato-Scott et al., 2020). However, more can be done to improve the quality of life for children with UI, and their carers. And indeed also for those children that may never be comfortable using public latrines, especially at night, and who may instead choose to urinate and/or defecate elsewhere – including on themselves.

Research conducted in Bangladesh and Uganda found that there was clearly stigma associated with UI, and it would be reasonable to assume that this will always be the case (as per research conducted across multiple and diverse low- and middle-income contexts (Rosato-Scott et al., 2020)). Normalisation of the condition, with key messages including that UI is a medical condition but that most children will grow-out of it, would contribute to improving the quality of life for children with UI (and their caregivers) by reducing the protection challenges associated with the condition, and the social and emotional impacts too. The distribution of products known to support the management of the condition (including mattress protectors and extra supplies for washing including buckets, soap and washing lines) would also be beneficial and the results of this research have informed UNICEF's work as it begins to investigate the supply of incontinence kits during an emergency (albeit focused on adults) (Shaylor, 2022).

Using the Story Book methodology to improve the quality of life of children with UI

When resources allow, the Story Book methodology would be a useful research tool to better understand how to meet the needs of children who self-wet due to the medical condition of UI (and indeed those experiencing social incontinence), and their caregivers, with findings used to provide a better understanding of a) how to normalise the condition in the affected population and b) which products would be best suited to help families manage self-wetting in the home. Until then, the findings of such studies can be used to ensure that self-wetting remains on the agenda of both researchers and practitioners, and to improve the quality of the generalised assistance that can be given in the early stages of a humanitarian response.

Personal reflections on the PhD

When I was a Master's student studying Water and Sanitation for Development, I chose to focus my thesis on incontinence experienced by adults in Zambia. I was attracted to the opportunity to conduct formative research, and to contribute to improving real-life WASH programmes. Before I started the research, I imagined that the focus would be on understanding how to better provide water and soap to rural communities. What I found was that the stigma surrounding incontinence was so complex, so nuanced, that actually what was needed was a better understanding of the attitudes towards the condition itself. I – and the wider research team – hadn't appreciated the social and emotional impact of the condition, and the associated protection-related challenges.

I started my PhD a year later, having had a year on maternity leave. I was still intrigued by incontinence, and still excited by the prospect of conducting formative research to improve the quality of life for potentially millions of people (I was ambitious!). My first task was to discover the research gaps and decide where to focus. On the one hand that was easy, as there had been so little research conducted on incontinence in low- and middle-income contexts. But narrowing down the list of potential topics was trickier. Having not long ago had a child, I was drawn to female experiences of incontinence before and after birth. But then a few anecdotes about children wetting themselves in refugee camps really grabbed my attention, and it wasn't long before I'd settled on a topic: emergency sanitation for children with urinary incontinence.

I learned a huge amount in the first year or so of reviewing literature. Understanding how best to manage incontinence in an emergency setting requires in-depth knowledge on the medical condition itself; sanitation in low- and middle-income contexts; and further, sanitation in an emergency setting – about which I had no real-life experience. But I enjoyed pulling-it together and it naturally resulted in my first paper, on the CHILD-SAN framework. In exploring new worlds in both health and emergency response, I became aware of a project being led by Save the Children on improving latrines and hand-washing facilities in Ethiopia and they very kindly allowed me to get involved.

By that time I had fallen down a path of desperately trying to understand just how many children could be experiencing UI in an emergency setting. It was largely because the numbers were potentially vast and I struggled to comprehend why then so little had been done on this topic, but also to justify interest in this area (by both myself, academics and humanitarian practitioners). I read far too many studies on the prevalence of UI, none of which were based in an emergency setting, and spent far too long trying to figure out if I could extrapolate what prevalence could be in an emergency context. It was a fool's

errand – UI is notoriously difficult to diagnose, and the studies that had been completed found wildly different estimates due to differing definitions and methodologies. I therefore grabbed the opportunity to work with Save the Children, and by then Eclipse Experience, to use their survey to get some real-life data on UI.

What we found was very little, in terms of the numbers at least. But again, as always with UI, the picture was complex. There were clear indications that there were children wetting themselves, even if this wasn't disclosed in the numbers. By this point I realised that the focus of my PhD had to change. For a start, it was highly unlikely that I would ever be able to determine a prevalence number given the stigma associated with the condition and the reluctance of families to disclose UI. But secondly, by now I was really beginning to question if it was even important. Even if somehow, I could calculate the prevalence of UI in an emergency context, it would not be applicable elsewhere so what would be the benefit? I'd also started to appreciate that it wasn't just UI that I needed to think about, as the role of social incontinence also began to become clear – I started to talk about 'self-wetting' and 'children wetting themselves' (that is, regardless of causation) rather than thinking in limited terms about only children with the medical condition of UI. So the focus needed to change from needing to know how many children could have UI to justify interest in the topic, to understanding what the impact of self-wetting on children and their caregivers is to justify its place on the agenda of both academics and humanitarian practitioners.

Luckily Elrha believed the same, with its HIF launching a funding round in 2019 focused on understanding the impact of incontinence in humanitarian settings. I was fortunate enough to be a lead researcher on a proposal that was eventually awarded funding. With this grant, the possibilities for my PhD suddenly became tremendous – I was going to lead the development of a brand-new methodology to engage with children, in an emergency setting, on a personal and sensitive health issue – for the first known time. I was going to travel to Bangladesh and Uganda to witness first-hand the challenges of humanitarian contexts faced by affected populations, researchers and humanitarian practitioners. And I was going to be able to analyse data that would hopefully inform new policy to improve the quality of life for children in emergency contexts. My biggest challenge was to figure out what to include in my PhD given the number of options available! And then Covid-19 happened.

The UK went into lockdown a month or so after the HIF had hosted a launch event for its grantees in Amsterdam, The Netherlands. We had project partners in place in both Bangladesh and Uganda, and I had started to meet with experts in conducting research

with children to better understand how to engage with children aged five to 11 on personal and sensitive health issues. I started to develop the Story Book methodology and gathered feedback from project partners via online meetings. The timelines of a supposedly 18-month project were impacted by both paperwork between the project partners (unforeseen), and getting ethical clearance from the requisite bodies in the UK, Bangladesh and Uganda (for which we should have allowed more time for, lesson learned!).

As time ticked on and Covid-19 restrictions continued, the chances of me being able to conduct the research myself slimmed as I approached a second maternity leave. Although personally disappointing, there were still potentially options for my PhD given that I was leading the development of the methodology, but a lot would depend on what happened next with the project and when – all of which was out of my control. Around the same time, I was also completing an evaluation of the methodology used by Save the Children and Eclipse Experience in Ethiopia, and I had to start thinking about whether this would in fact need to become the focus of my PhD. Again this was impacted by Covid-19 – interviews had to be completed remotely using teleconferencing software, even with UK-based participants; and access to Tukaley village in Ethiopia was restricted so participants from the study couldn't be interviewed.

By the time I went on maternity leave in November 2020, there was still no firm plan in place for conducting the research and Covid-19-related travel bans were still restricting any UK- or Australia-based members of the research team from visiting either Bangladesh or Uganda. Over the next year or so of continued restrictions, the approach had to shift. Existing relationships with in-country project partners deepened, and new ones were started with research organisations in-country actually able to conduct the research themselves.

I returned from maternity leave in November 2021, just after the research was conducted in Bangladesh and in-time for the research to be conducted in Uganda. But my role in the project had to adapt to the change in approach. I could no longer in good conscience analyse data that I hadn't collected myself, in a country I hadn't visited, in a language I didn't speak. My role became more supportive as the in-country teams, rightly so, led the analysis efforts. I spun-off my own project, focused on evaluating the methodology given my role in its development and my ability to provide an objective viewpoint on how it was implemented versus its design.

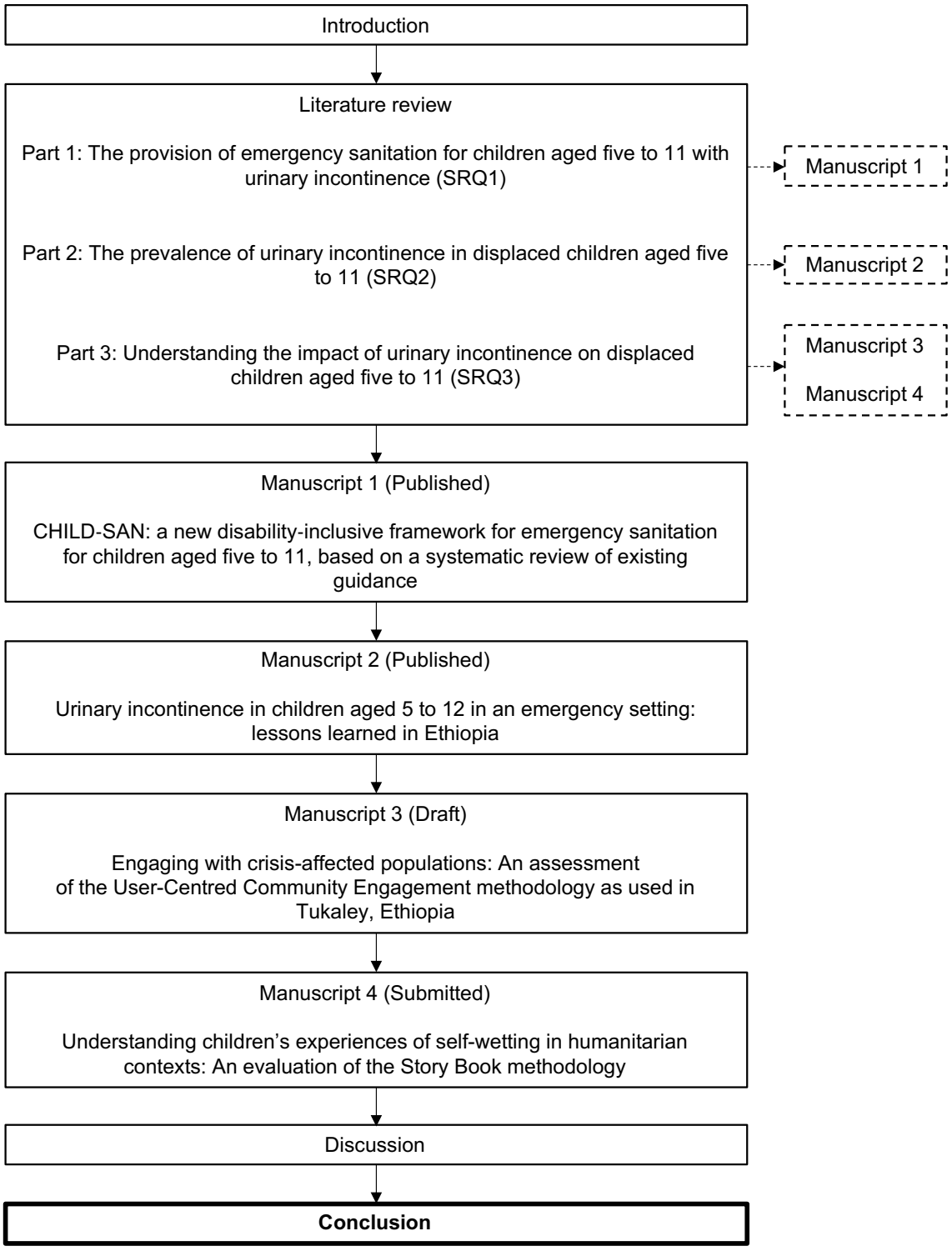
In hindsight, I should never have planned to conduct the research myself. Researchers need to be known to the communities being asked to participate in studies. They should ideally speak their language and understand their cultures. Not only because it makes for a much better experience for the participants, but also because the researchers themselves are able to understand the data collected with far more depth and clarity relative to, well in this instance, me. They're also better placed to follow-up on actions that are taken as a result of the research. That's not to say there isn't a role for non-country-based researchers. Experts from anywhere can advise, particularly on unusual and complicated topics such as conducting research with children, in humanitarian settings, on a personal and sensitive health issue. And there is probably an argument that the projects would have benefited from such experts having an in-country presence at times, for example, during training. But ultimately the project was better for Covid-19 happening.

I'm not sure that my PhD is better for Covid-19 happening, however. Four years of research later (albeit one of which was spent on maternity leave), and I haven't stepped foot in an emergency setting; I haven't even been able to conduct a single interview in-person. It was not the experience I was hoping for, and although I have learned a huge amount along the way, that lack of personal experience was really felt as I came to try and pull together the 'so what' section of the PhD. The 'how does this impact the wider world' thinking that ultimately I found the most challenging because I lacked personal reference points. Luckily, I had colleagues and project partners with the personal experience I lacked that were able to provide guidance.

Now I have pulled everything together, I am impressed with how much multiple project teams have managed to achieve in extremely difficult circumstances. Thinking that a PhD reliant on conducting research in humanitarian settings would be plannable was a little naïve, but of course I could have no way foreseen a global pandemic and the impact that would have so to have been part of so much is an achievement. When I signed-up to do a PhD, I wanted to work on something that would have true impact on the real-lives of people experiencing self-wetting. It is a little overwhelming to realise as I write this that I've achieved that – the results of the research conducted in Bangladesh, Ethiopia and Uganda will improve the quality of life of the participants and their wider communities. In fact, even just doing the research itself had a positive impact on the children able, for the first time, to have their voices heard. But I have also been able to contribute further than that, with the CHILD-SAN framework and associated checklist; with an approach on how to conduct research with children in humanitarian contexts; and with the Story Book methodology. These are long-lasting tools that practitioners (development and

humanitarian) can use anywhere to improve the provision of sanitation facilities for all children aged five to 11 – including those that wet themselves – and in doing so, improve their quality of life and that of their caregivers. And for achieving that, I am very proud.

Emergency sanitation for children with urinary incontinence (Rosato-Scott)



Conclusion

First, a reminder on lexicology. The seed of this PhD was planted when the author heard a few anecdotes from NGO workers observing that children in refugee camps were wetting the bed at night. The assumption at that time was that this was due to them experiencing the medical condition of UI, caused by the stresses and anxiety of being a displaced child. Following more conversations with humanitarian practitioners, it soon became clear that much of that bed-wetting could actually be due to the children not wanting, or not being able, to use the sanitation facilities provided. This is defined as social, or functional incontinence. The term 'self-wetting' has therefore been used throughout this PhD when the causation of self-wetting is unknown, or when referring to a group of children self-wetting of which some will be due to UI and some due to social incontinence.

Social incontinence in children aged five to 12 is best managed during an emergency by providing sanitation facilities that children want, and are able, to use: ideally by using the CHILD-SAN framework as a starting-point for the design of sanitation facilities, and crucially by also facilitating the participation of the children themselves in the design of sanitation facilities as soon as possible (and the UCCE methodology has demonstrated that this can be done even when there are limited resources – time, financial, technical, people – available).

But there will always be children that wet themselves, due to experiencing either social incontinence (despite best efforts, some children may just never feel comfortable enough to use public latrines, especially at night) or UI. It doesn't matter how many, what matters is that humanitarian programmes can by default begin to better support such children. Research conducted in Bangladesh, Ethiopia and Uganda all found a level of stigma around self-wetting that contributed to negative consequences including punishment of the child, and social isolation within the community. Communication to support the normalisation of the condition is therefore a critical first step to be taken, and can be as simple as educating humanitarian practitioners across sectors on the condition so that they can spread positive messages about it. The inclusion of products in standardised hygiene kits to support the management of self-wetting would also help, notably mattress protectors and extra supplies for washing including buckets, soap and washing lines.

The provision of such communications and incontinence kits can be improved if children continue to be asked about their experiences of self-wetting, and this can be done using the Story Book methodology as soon as circumstance and resources allow. Ultimately,

it is unlikely that in an emergency context it will be possible to diagnose children with UI and/or provide medical treatment. But measures can be taken to support families to manage the condition, and subsequently improve their quality of life. And children have a right for their thoughts to be heard on just what those measures should be.

References (Discussion and Conclusion)

Abrams, P., Cardozo, L., Wagg, A. and Wein, A. (eds.). 2017. Incontinence 6th Edition [Online]. Bristol, UK: ICI-ICS. International Continence Society. [Accessed 9 November 2021]. Available from: https://www.ics.org/education/icspublications/icibooks/6thicibook.

American Psychiatric Association 2013. Diagnostic and statistical manual of mental disorders (DSM-5) 5th ed. Washington DC, United States: American Psychiatric Publishing.

Austin, P.F., Bauer, S.B., Bower, W., Chase, J., Fanco, I., Hoebeke, P., Rittig, S., Walle, J. Vande, von Guntard, A., Wright, A., Yang, S.S. and Nevéus, T. 2016. The Standardization of Terminology of Lower Urinary Tract Function in Children and Adolescents: Update Report From the Standardization Committee of the International Children's Continence Society. Neurourology and Urodynamics. 35, pp.471–481.

Buckley, B.S. and Lapitan, M.C.M. 2010. Prevalence of Urinary Incontinence in Men, Women, and Children - Current Evidence: Findings of the Fourth International Consultation on Incontinence. Urology. 76(2), pp.265–270.

Buckley, B.S., Sanders, C.D., Spineli, L., Deng, Q. and Kwong, J.S.W. 2019. Conservative interventions for treating functional daytime urinary incontinence in children.

Curtis, P., Thompson, J. and Fairbrother, H. 2018. Migrant children within Europe: a systematic review of children's perspectives on their health experiences. Public Health. 158, pp.71–85.

Eclipse Experience 2019. User-Centred Community Engagement. [Accessed 16 November 2021]. Available from: http://www.eclipse-experience.com/user-centred-community-engagement.

Eclipse Experience 2020. User-Centred Community Engagement: Ethiopia Pilot Outcomes [Online]. [Accessed 13 July 2022]. Available from: https://static1.squarespace.com/static/5818a9ed2994ca08210fdb36/t/5e58f703086b4403a35fa8e1/1582888711651/UCCE_Ethiopia+Pilot+Outcomes.pdf.

Esezobor, C.I., Balogun, M.R. and Ladapo, T.A. 2015. Prevalence and predictors of childhood enuresis in southwest Nigeria: Findings from a cross-sectional population study. Journal of Pediatric Urology. 11, pp.1–6.

Järvelin, M.R., Moilanen, I., Vikeväinen-Tervonen, L. and Huttunen, N. 1990. Life Changes and Protective Capacities in Enuretic and Non-Enuretic Children. Journal of Child Psychology and Psychiatry. 31(5), pp.763–774.

Joinson, C., Sullivan, S., Von Gontard, A. and Heron, J. 2016. Stressful Events in Early Childhood and Developmental Trajectories of Bedwetting at School Age. Journal of Pediatric Psychology. 41(9), pp.1002–1010.

Keith, R. Mac 1968. A Frequent Factor in the Origins of Primary Nocturnal Enuresis: Anxiety in the Third Year of Life. Developmental Medicine and Child Neurology. 10(4), pp.465–470.

Kohrt, B.A., Mistry, A.S., Anand, N., Beecroft, B. and Nuwayhid, I. 2019. Health research in humanitarian crises: An urgent global imperative. BMJ Global Health. 4(6), pp.1–8.

Mistry, A.S., Kohrt, B.A., Beecroft, B., Anand, N. and Nuwayhid, I. 2021. Introduction to collection: confronting the challenges of health research in humanitarian crises. Conflict and Health. 15(1), pp.1–6.

Morison, M., Staines, H. and Gordon, A. 2004. A systematic review of the prevalence of nocturnal enuresis In: ICS/IUGA [Online]. Paris, France. [Accessed 9 November 2021]. Available from: https://www.ics.org/Abstracts/Publish/42/000093.pdf.

O'Kane, C. 2013. Review of children's participation in humanitarian programming [Online]. London, United Kingdom. [Accessed 11 January 2022]. Available from: https://resourcecentre.savethechildren.net/document/review-childrens-participation-humanitarian-programming/.

Oxfam International and WEDC. 2018. Shining a Light: How lighting in or around sanitation facilities affects the risk of gender-based violence in camps. [Online]. [Accessed 20 February 2019]. Available from: https://oxfamilibrary.openrepository.com/bitstream/handle/10546/620605/gd-shining-light-sanitation-gender-211218-en.pdf?sequence=1.

Rosato-Scott, C., Alam, M., Evans, B.E., Rose, J., Wozei, E. and Barrington, D.J. tbc. Understanding children's experiences of self-wetting in humanitarian contexts: An evaluation of the Story Book methodology (Submitted). PLOS Global Public Health.

Rosato-Scott, C., Barrington, D.J., Bhakta, A.N., House, S., Mactaggart, I. and Wilbur, J. 2020. Incontinence: We Need to Talk About Leaks [Online]. Brighton: IDS. Available from: https://doi.10.19088/SLH.2020.005.

Rosato-Scott, C., Evans, B.E. and Barrington, D.J. 2021a. CHILD-SAN: a new disability-inclusive framework for emergency sanitation for children aged five to 11, based on a systematic review of existing guidance. Journal of International Humanitarian Action. 6(1).

Rosato-Scott, C. and Barrington, D.J. tbc. Engaging with crisis-affected populations: An assessment of the User-Centred Community Engagement methodology as used in Tukaley, Ethiopia. Journal of Humanitarian Affairs. tbc.

Rosato-Scott, C.A. and Barrington, D.J. 2018. Incontinence in Zambia: initial investigation into the coping strategies of sufferers and carers. Waterlines. 37(3), pp.190–206.

Rosato-Scott, C.A., Evans, B.E., Varampath, A., Fehnert, B. and Barrington, D.J. 2021b. Urinary incontinence in children aged 5 to 12 in an emergency setting: lessons learned in Ethiopia. Waterlines. 40(3), pp.179–191.

Shahabuddin, A.S.M., Sharkey, A.B., Jackson, D., Rutter, P., Hasman, A. and Sarker, M. 2020. Carrying out embedded implementation research in humanitarian settings: A qualitative study in Cox's Bazar, Bangladesh. PLoS Medicine. 17(7), pp.1–13.

Shaylor, E. 2022. Email exchange with Claire Rosato-Scott 1 April 2022.

Spencer, G., Smith, M., Thompson, J., Fairbrother, H., Hoare, K., Fouché, C. and Curtis, P. 2019. Health experiences of children and young people who migrate-Opportunities for health education. Health Education Journal. 78(1), pp.96–107.

Sphere Association 2018. The Sphere Handbook: Humanitarian Charter and Minimum Standards in Humanitarian Response [Online] 4th ed. Geneva, Switzerland: Sphere Association. [Accessed 5 November 2021]. Available from: https://spherestandards.org/handbook-2018/.

United Nations 2015. Resolution adopted by the General Assembly on 17 December 2015. 70/169. The human rights to safe drinking water and sanitation. [Accessed 23 September 2023]. Available from: https://undocs.org/en/A/RES/70/169.

United Nations 2016. Sustainable Development Goal 6. [Accessed 5 November 2021]. Available from: https://sustainabledevelopment.un.org/sdg6.

United Nations Committee on the Rights of the Child 2009. General Comment No.12. on the Right of the Child to be Heard [Online]. Geneva, Switzerland. Available from: https://www.refworld.org/docid/4ae562c52.html.

WHO 2006. Constitution of the World Health Organisation [Online]. Geneva, Switzerland. [Accessed 5 November 2021]. Available from: https://www.who.int/governance/eb/who_constitution_en.pdf.

WHO 2018. ICD-11 definition of Enuresis. [Accessed 9 November 2021]. Available from: https://icd.who.int/browse11/l-m/en#/http%3A%2F%2Fid.who.int%2Ficd%2Fentity%2F1157749237.

Appendices

A1 Lower urinary tract conditions

Normal bladder storage and voiding involves:

1. low pressure and adequate bladder volume filling, followed by
2. a continuous detrusor (the smooth muscle found in the wall of the bladder) contraction to empty the bladder, associated with
3. adequate relaxation of the urethral sphincter complex (Abrams et al., 2017).

The ICCS has classified the following abnormalities in the storage and voiding stages of the urination cycle (Austin et al., 2016) (Table 5):

Table 10 Abnormalities in the storage and voiding stages of the urination cycle

Condition	Description
Urgency	Sudden and unexpected immediate and compelling need to urinate (applicable only once bladder control has been attained), usually attributable to an overactive bladder due to detrusor overactivity
Stress incontinence	Discrete leakage of urine with effort or physical exertion, for example, coughing or sneezing
Giggle incontinence	Extensive emptying or leakage of urine during or immediately after laughing only
Extraordinary daytime only urinary frequency	Daytime urination of small volumes (typically 10 to 15% of estimated bladder capacity) at least once per hour, but UI is rare
Overactive bladder (OAB)	Urinary urgency, usually accompanied by frequency and nocturia, with or without urinary incontinence, in the absence of a urinary tract infection or other obvious cause
Underactive bladder	Straining to initiate, maintain or complete urination, usually attributable to detrusor underactivity
Dysfunctional voiding	Contraction of the urethral sphincter or pelvic floor during urination
Voiding postponement	Postponement of urination using holding manoeuvres (often with urgency and DUI due to a full bladder)
Vaginal reflux	Daytime incontinence shortly after urinating with no other lower urinary tract symptoms or enuresis, due to urinating with adducted legs (leading to urine entrapment inside the vaginal opening)

Bladder outlet obstruction (BOO)	An impediment of urine flow during urination (mechanical or functional)
Bladder neck dysfunction	Impaired or delayed opening of the bladder neck resulting in reduced flow

A2 Interactions with specialists

Table 11 Specialists

Name		Organisation
Anne	Cabrera-Clerget	UNICEF (Supply)
Anna	Crowle	Independent
Pete	Culmer	University of Leeds
Claudio	Deola	Save the Children
Iffat	Farhana	UNICEF
Michelle	Farrington	Oxfam
Suzanne	Ferron	Independent
Toby	Gould	Independent
Clare	Harley	University of Leeds
Anna-Lena	Hellström	Gothenburg University
Sarah	House	Independent Consultant
Amy	Hunter	University of Leeds
Gheed	Jabbar	IRC
Carol	Joinson	University of Bristol
Sarah	King	University of Leeds (IMPRESS)
Ashok	Kumar	School of Planning and Architecture, New Delhi
Annie	Lloyd	Independent
Ian	Milsom	University of Gothenburg
Tryggve	Nevéus	ICCS / Upsala University (Sweden)
June	Rogers	Bladder and Bowel UK (Disabled Living)
Esther	Shaylor	UNICEF (Supply)
Brooke	Yamakoshi	UNICEF (Programmes)

A3 Systematic literature review: Methodology and results

A systematic method was used to search for English publications which systematically reviewed epidemiological studies of urinary incontinence in children (Criterion 1) (Figure 5). A search of the peer-reviewed literature was completed on 9 November 2021, and performed using ten databases which were selected as applicable from the extensive database list provided by the University of Leeds. A search protocol was developed focusing on a number of key words and the initial search yielded 1,473 documents (Table 8). A review of the title and abstract excluded all documents that were not systematic reviews of epidemiological studies of urinary incontinence in children aged five to 11 (Criterion 2), and the number of documents that were deemed appropriate for use was reduced to one (which appeared in several databases).

To identify grey literature records for inclusion the following were screened: a) websites of continence organisations including the Children's Bowel and Bladder Charity (ERIC), the International Children's Continence Society, and the International Continence Society, and b) Google. A request for information was also sent to known experts in UI in children. Three documents were subsequently identified.

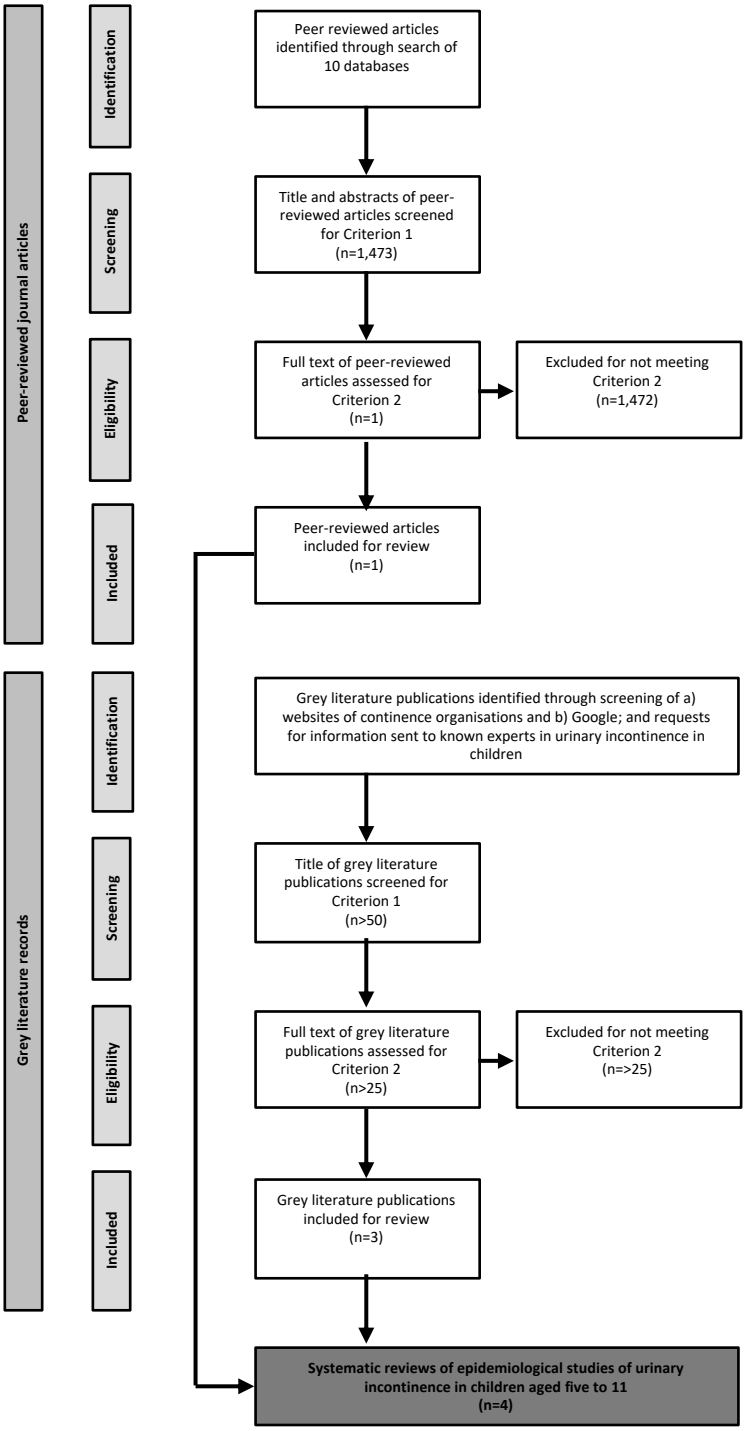


Figure 7 Systematic review: Methodology

Process of identifying peer-reviewed and grey literature publications for review. Criterion 1: English publications which systematically reviewed epidemiological studies of urinary incontinence in children. Criterion 2: English publications which systematically reviewed epidemiological studies of urinary incontinence in children aged five to 11. The figure was developed from the PRISMA Statement (Moher et al., 2009).

Table 7 Peer-reviewed literature search details and results

Database	**Search terms**	**Items returned**	**Items following review of title and abstract**
Cochrane Database of Systematic Reviews	'(incontinence OR enuresis OR leakage) AND child' in 'Title, abstract, keyword' filtered by 'Cochrane Reviews'	29	None
EBSCO	"systematic review" AND (incontinence OR enuresis OR leakage) AND child in 'Abstract'	28	None
Global Health	"systematic review" AND (incontinence OR enuresis OR leakage) AND child	15	Makrani *et al.*, 2015
Medline	"systematic review" AND (incontinence OR enuresis OR leakage) AND child	156	None
NHS Evidence (National Institute for Health and Care Excellence)	'(incontinence OR enuresis OR leakage) AND child' filtered by 'Systematic Reviews'	117	None
PROSPERO (International prospective register of systematic reviews)	(incontinence OR enuresis OR leakage) AND child	148	None
PubMed	"systematic review" AND incontinence OR enuresis OR leakage AND child in 'Article title, abstract, key terms' in 'Title/Abstract'	24	None
Scopus	"systematic review" AND (incontinence OR enuresis OR leakage) AND child in 'Article title, abstract, keywords	356	Makrani *et al.*, 2015

TRIP	'(incontinence OR enuresis OR leakage) AND child' filtered by 'Systematic Reviews'	406	None
Web of Science	"systematic review" AND (incontinence OR enuresis OR leakage) AND child	194	Makrani *et al.*, 2015
	Total	1,473	1 (Makrani *et al.*, 2015)

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REPORT Open Access

CHILD-SAN: a new disability-inclusive framework for emergency sanitation for children aged five to 11, based on a systematic review of existing guidance

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Abstract

The specific sanitation needs of children aged five to 11 years old—those too old to use small potties, but usually too young to safely and confidently use adult latrines during both the day and night, and including children in this age range with disabilities—have often been overlooked in the provision of emergency sanitation. There are multiple reasons to provide sanitation specifically for this age group. They represent a large number of beneficiaries; legal principles and the moral obligations of humanitarian actors should drive their inclusion. Failure to consider their needs results in increased risk of injuries, abuse and/or exploitation when using unsuitable locations to urinate or defecate, and negative health impacts arising from being unable to manage personal hygiene.

We have critically reviewed existing guidance for the provision of emergency sanitation for children aged five to 11 and subsequently presents a new disability-inclusive framework: CHILD-SAN. CHILD-SAN is an acronym representing key factors for the water, sanitation and hygiene (WASH) sector to consider in emergency sanitation programmes: **c**hild participation, **h**eights, user-fr**i**endly, **l**ocation, **d**écor, **s**caled-down, **a**ccessibility, and mo**n**itoring and evaluation.

The CHILD-SAN framework recommends (a) safe and meaningful child participation in emergency WASH preparedness planning and emergency WASH programming as a means to develop contextually-appropriate facilities, (b) specific design considerations for child-friendly toilets (that is, they meet the needs of a child), and (c) the collection of sex-, age- and disability-disaggregated data against contextually appropriate indicators to determine the prevalence of child-friendly facilities and their use. We found few examples of emergency WASH programmes adhering to elements of the CHILD-SAN framework, but the implementation of CHILD-SAN would contribute to the WASH sector's aims of achieving universal sanitation and maximising opportunities for good health, dignity, comfort and safety for all.

Keywords: Children, Disability, Incontinence, Latrine, Monitoring, Participation, Rights, Sanitation, Toilet

Introduction

Context

An 'emergency' is a subjective concept which can be defined as 'a situation that threatens the lives and well-being of large numbers of a population and requires extraordinary action to ensure their survival, care and protection' (UNICEF 2010, p.4). In an emergency, community and state institutional structures and services are ruptured, and families and communities are broken-up or displaced (Tanner and O'Connor 2017). In such contexts, children are particularly vulnerable. The Core Commitments for Children in Humanitarian Action outline programme commitments for the initial response

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to an emergency, with the water, sanitation and hygiene (WASH) sector aiming to prevent and reduce mortality and morbidity by minimising the spread of disease (UNICEF 2010). In addition, WASH actors are expected to ensure that all people have access to adequate and equitable sanitation and hygiene, and the maximisation of opportunities for good health (defined by the World Health Organisation (WHO) as complete physical, mental and social well-being), dignity, comfort and safety (WHO 2006; United Nations 2016; Sphere Association 2018; Groupe URD 2019). Whilst these aspects should be considered from the beginning, increasing attention and time will be spent on ensuring their achievement over time.

There has been a reasonable amount of research into how emergency WASH interventions provide sanitation for both children under-5 years old (due to the significant health risks their faeces represent) and adults (aged 18 years and over) during both the initial and longer-term response. Yet the specific sanitation needs of those too old to use small potties but usually too young to safely and confidently use adult toilets during both the day and night (defined for our purposes as aged from 5 to 11 years old), and including children with disabilities, are often overlooked (Visser 2012).

Children and emergencies

Cultural definitions of the upper limit of childhood may vary, but the United Nations (UN) Convention on the Rights of the Child (CRC) defines a child as 'every human being below the age of 18 years unless under the law applicable to the child, majority is attained earlier' (Part I, Article 1) (UN 1990). While the specifics of definitions may vary, the general point remains; children are particularly vulnerable in an emergency and children under 15 'suffer the most' (Global WASH Cluster 2019, p.7).

The United Nations Office for the Coordination of Humanitarian Affairs (OCHA) estimates that in 2021, 235 million people will need humanitarian assistance and protection. This means 1 in 33 people worldwide needs help (OCHA 2020, p.9). At the end of 2019, the United Nations High Commissioner on Refugees (UNHCR) estimated that there were 87.63 million persons of concern, being any person whom the UNHCR considers to be a refugee, a returnee, stateless, internally displaced or an asylum-seeker (UNHCR 2020). Of these, the UNHCR had demographic data on 36 million: over half (19 million) were under 18 years of age, and 1 in 5 (7.86 million) were aged between 5 and 11 years of age (UNHCR 2020).

During the disruption of an emergency children of any age and ability face a range of heightened risks—particularly if separated from family and/or caregivers—including disease, a disrupted education, gender-based violence including sexual violence and exploitation, malnutrition, neglect, physical and emotional abuse, psychosocial distress, trafficking and recruitment into armed groups (Tanner and O'Connor 2017; Sphere Association 2018; UNICEF 2018). Further, whilst usually dependent on others to provide their needs, including safe food and water, shelter and healthcare, in an emergency children may necessarily be dependent on adults who are not be part of their usual network of caregivers.

The Core Commitments for Children in Humanitarian Action (CCCs) are a global framework for humanitarian action for all children guided by international human rights law (including the Convention on the Rights of the Child and international humanitarian law), and based on global standards and norms for humanitarian action (UNICEF 2010). The CCCs outline the programme commitments for action in the first 8 weeks of an emergency response and provide guidance for action beyond that period by six sectors: nutrition, health, HIV and AIDS, education, child protection, and WASH (UNICEF 2010).

The WASH sector in an emergency

Oxfam (2013, p.4) considers that 'WASH' incorporates water (clean water supply for human consumption, hygiene and household needs), sanitation (excreta disposal, solid waste management, drainage and vector control) and hygiene (community mobilisation and engagement, information, education and communication, non-food item distributions and health data monitoring). In the first stages of an emergency response, the core mandate of WASH interventions is to prevent and reduce mortality and morbidity by minimising the spread of disease, primarily through the separation of humans from faecal matter. They are 'not necessarily intended to provide long-term sustainable access, but instead provide rapid relief' (Yates et al. 2018, p.32).

The WHO recognises four stages of response to an emergency, with timings being context-specific: first steps (normally the first week), emergency response (normally the first month), continuing response/consolidation (beyond the first month) and phasing out/recovery (WHO 2008). WASH interventions must adapt as the emergency progresses to beyond providing 'rapid relief' in the initial (first steps and emergency response) phases. In the continuing response/consolidation phase, efforts aim to shift from the provision of communal solutions to culturally appropriate and sustainable household-level solutions informed by the equitable participation of the affected population (Gensch et al. 2018). During the phasing out/recovery phase, infrastructure development continues and the participation of stakeholders continues to increase, to facilitate handover to households or local and longer-term partners (Gensch et al. 2018).

Humanitarian Response Plans (HRPs) are prepared for a protracted or sudden onset emergency that requires international humanitarian assistance (OCHA 2019). Initially prepared for a year, they are annually updated as the emergency progresses: the average length of an HRP, and therefore the associated emergency response, is 9.3 years (OCHA 2018). During that time, there will be multiple WASH interventions, with differing objectives. The Sphere Handbook (Sphere Association 2018) is generally considered by the humanitarian sector to represent best practice guidance for the delivery of emergency sanitation interventions. Sphere states that a key activity of emergency WASH interventions is 'ensuring conditions that allow people to live with good health, dignity, comfort and safety' (Sphere Association 2018, p.92), with the WHO defining health as 'a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity' (WHO 2006). Further, the Sustainable Development Goals (SDGs) aim to 'achieve access to adequate and equitable sanitation and hygiene for all … paying special attention to the needs of women and girls and those in vulnerable situations' by 2030 (SDG Target 6.2) (United Nations 2016). Prior to the SDGs, the main priority had been the provision of basic sanitation at the household level with other settings receiving less attention: to achieve universal access other settings now need to be considered, including those of involuntarily displaced populations (Behnke et al. 2018).

It is within this context that we seek to (a) critically review existing guidance for the provision of emergency sanitation for children specifically aged five to 11 (being those too old to use small potties, but usually too young to safely and confidently use adult toilets during both the day and night, including children with disabilities), (b) present a new disability-inclusive framework (CHILD-SAN) that the WASH sector can use to better provide emergency sanitation for this somewhat forgotten age group and (c) critically assess existing facilities against the CHILD-SAN framework.

Methods

Systematic review

A systematic method was used to search for publications which (a) discussed or reported on emergency sanitation for children; (b) were published in 2004 or later, being the year that the Sphere Handbook (Sphere Association 2018) first included children as a cross-cutting theme; and (c) were written in English or Spanish (being the languages spoken by the lead author) (Criterion 1). Full texts of publications that met Criterion 1 were assessed to determine whether they provided guidance on (Criterion 2a) and/or reported on the provision of emergency sanitation for children (Criterion 2b), including those aged five to 11. The publications which met Criterion 2a and/or b were qualitatively analysed (Fig. 1).

A search of the peer-reviewed literature was conducted on March 3, 2019. The Scopus and Web of Science databases were searched for articles published since 2004 using the search string '(emergency OR disaster OR humanitarian OR crisis) AND (sanitation OR toilet OR latrine OR 'solid waste management') AND (child*)' which returned 247 and 233 results, respectively. The titles and abstracts (where necessary) of these records were screened according to Criterion 1, resulting in 21 articles from which eight duplicates were removed. Each article was then assessed to determine whether it met Criterion 2a and/or 2b, of which six did.

To identify grey literature records for inclusion the following were screened: (a) bibliographies of the six peer-reviewed articles which met Criterion 2a and/or 2b; (b) the websites of the 41 organisations that are full members of the Global WASH Cluster[1]; and (c) Google using the search term 'emergency sanitation children' (with the first 120 results assessed, after which saturation was reached as results were not relevant). Requests for information were also sent to known experts in the Emergency WASH sector, including to an informal email group of individuals with an interest in incontinence in low- and middle-income countries (44 members at time of the request, December 17, 2018), and to the Emergency WASH Google Group which is maintained by the Global WASH Cluster and USAID (227 members at time of the request, March 13, 2019). The full text of each publication that met Criterion 1 was assessed to determine whether it met Criterion 2a and/or 2b.

The bibliographies of all grey literature publications that met Criterion 2a and/or b were screened for publications that met Criterion 1, with the full text of those that did assessed to determine if they met Criterion 2a and/or b. This process was repeated until no new publications were identified.

[1] The 41 organisations that are full members of the Global WASH Cluster are Action contra la Faim, Adventist Development and Relief Agency, Care International, Catholic Agency for Overseas Development, Catholic Relief Services, Clean the World Foundation, Concern Worldwide, German WASH Network, GOAL, International Federation of Red Cross and Red Crescent Societies, International Medical Corps, IMPACT Initiatives, International Organisation for Migration, International Rescue Committee, Islamic Relief, Medair, Mentor Initiative, Mercy Corps, Norwegian Church Aid, Norwegian Refugee Council, Oxfam International, Plan International, Polish Humanitarian Action, Population Services International, Red Cross Austria, Relief International, Samaritan's Purse, Save the Children UK, Solidarites International, Tearfund, Terre des Hommes, THW (Germany), World Vision, UN Development Programme, UN Environment Programme, UN Habitat, UN Refugee Agency, UN International Children's Emergency Fund, UN Relief and Works Agency, World Food Programme and World Health Organisation.

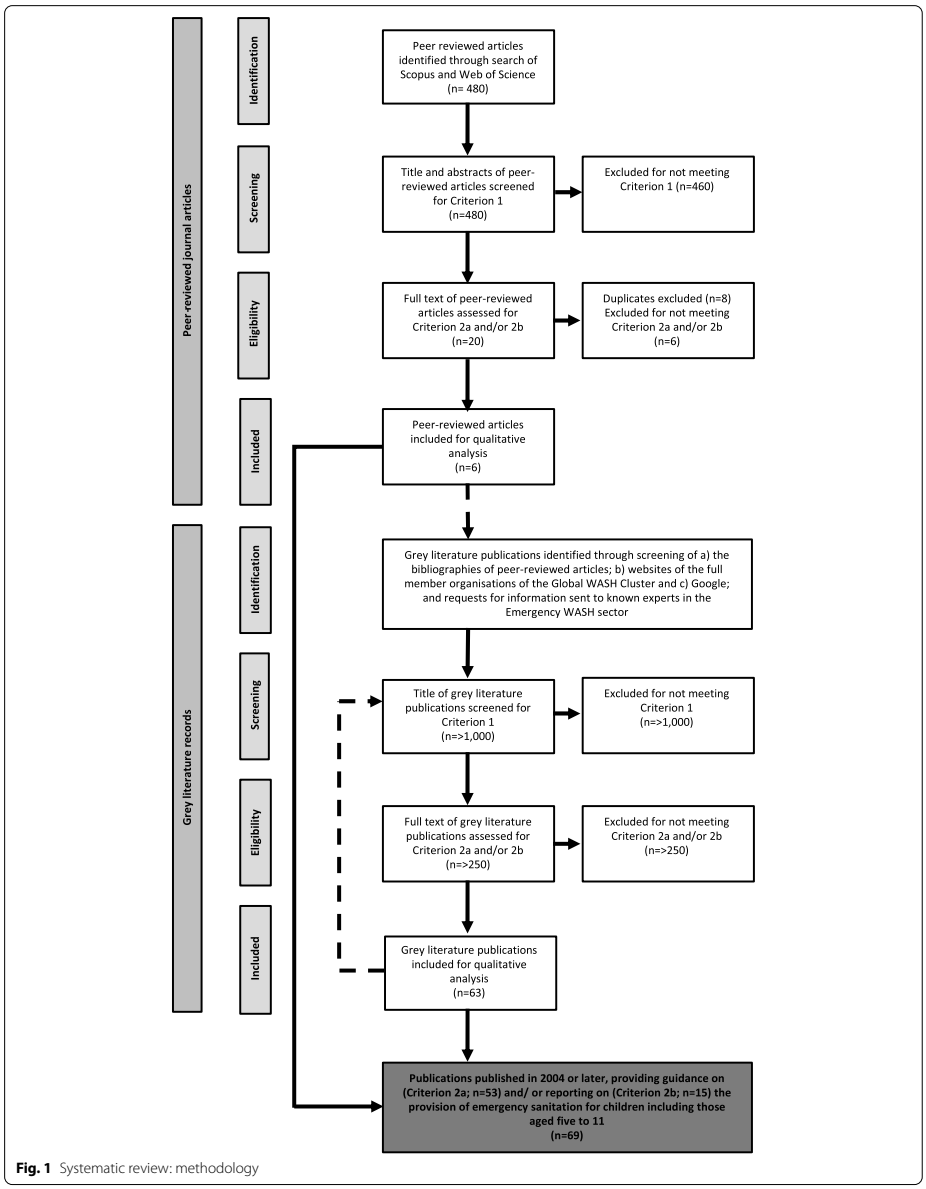

Fig. 1 Systematic review: methodology

Process of identifying peer-reviewed and grey literature publications for review. Criterion 1 being publications which (a) discussed or reported on emergency sanitation for children, (b) were published in 2004 or later, and (c) were written in English or Spanish. The 69 publications that met Criterion 2 were classified as either providing guidance on (Criterion 2a) or reporting on (Criterion 2b) the provision of emergency sanitation for children aged five to 11 (see Supplementary Information Table 1). The dashed lines indicate where bibliographies were used to identify further publications. The figure was developed from the PRISMA Statement (Moher et al. 2009).

Analysis

Publications that provided guidance on the provision of emergency sanitation for children including those aged five to 11 (Criterion 2a) were inductively coded using NVivo 12. The codes (Table 1) assigned a summative attribute to a portion of data and this system was used to identify emerging themes and to highlight pertinent excerpts which were specifically relevant to children aged five to 11. The identified themes were amalgamated to develop a new disability-inclusive framework for the provision of emergency sanitation for children aged five to 11: CHILD-SAN.

The publications that reported on the provision of emergency sanitation for children including those aged five to 11 were also inductively coded using NVivo 12. The codes (Table 2) assigned a summative attribute to a portion of data and this system was used to identify examples of emergency sanitation for children aged five to 11, or the monitoring and evaluation of emergency sanitation for children aged five to 11. Once identified, these examples were critically assessed against the newly developed CHILD-SAN framework. Note that some publications provided guidance on, and reported on, the provision of emergency sanitation for children including those aged five to 11. These publications were therefore coded twice.

Findings

The definition of 'sanitation'

The WHO defines sanitation as 'the provision of facilities and services for the safe management of human excreta … (and) also includes the safe management of solid waste and animal waste' (WHO 2018). Some authors of reviewed publications, including this one, prefer to broaden this definition from the protection of personal, public and environmental spaces: Langford et al. (2017, pp.348–349) for example, add that sanitation is also 'the ability to effectively access space and facilities (whenever and wherever needed) that afford privacy, dignity and safety in which to urinate, defecate and practice related hygiene, including menstrual health management, in a culturally acceptable manner.'

There is an extensive and diverse literature providing guidance for the delivery of emergency sanitation interventions. Emergency sanitation for children is referenced in varying degrees throughout the literature, but needs at different ages are rarely considered. Most guidance focuses on participation in behavioural change programme design (especially for hygiene management programmes, usually hand-washing before touching food and after contact with excreta) and excreta management (largely for children under the age of five) and hygiene promotion. Specific considerations for children aged five to 11 were found only with regard to the provision of toilets and handwashing facilities. Note that we have used the term 'toilet' to mean any 'facility or device that immediately contains excreta and creates the first barrier between people and the waste' (Sphere Association 2018, p.113).

A critical review of existing guidance

Guidance for the provision of emergency sanitation for children aged five to 11 generally fell into three categories: ensuring safe access, adaptations to facilitate use, and improving a child's experience of using a toilet.

Table 1 Codebook for Criterion 2a publications

Code	Definition of the text to which the code relates
Definitions	Definitions of key terms
Emergency statistics	Key data points related to emergencies
Guidance, general	General guidance for emergency WASH interventions
Guidance, M&E	General guidance for the monitoring and evaluation of emergency interventions
Response phases	Descriptions of emergency response phases
Response principles	General principles guiding the WASH-sector's response to emergencies
Solid waste management	Any reference to children and solid waste management
Toilets	Any reference to children and toilets (including latrines)

Table 2 Codebook for Criterion 2b publications

Code	Definition of the text to which the code relates
Examples, M&E	Real-life examples of the M&E of emergency interventions
Examples, sanitation	Real-life examples of emergency sanitation for children
Use of toilets statistics	Data points related to the use of toilets by children

Ensuring safe access

For a child to be able to use a toilet they must be able to safely access it, and the guidance notes that paths should be wide enough for two people (for example, a caregiver and child) to comfortably pass (Ferron and Lloyd 2014). We note that caregivers may not always be available or willing to accompany a child to the toilet however, for example, in cultures where the practice of *Purdah* is followed such as the Rohingya community in Cox's Bazar, Bangladesh (House 2019). Therefore, the ability of a lone child to navigate the approach (both in terms of distance and topography) must also be considered.

Adaptations to facilitate use

The guidance acknowledges that toilets need to be adapted for the use by children with disabilities, and because children are smaller and have less physical strength relative to adults (UNICEF 2012). Features to be adapted include the heights of door handles, locks and handrails (Save the Children 2013); toilet seat and squatting plate dimensions (Banzet 2003; Ferron and Lloyd 2014); the size of drop-holes (Noortgate and Maes 2010); and the ease of use of doors, taps for handwashing and water for anal cleansing (Zomerplaag and Moojiman 2005).

Within the existing guidance for emergency sanitation for children aged five to 11, UNICEF (2017b) provides indicative sizings for adaptations to be made to toilets for children with disabilities; Noortgate and Maes (2010) provide indicative child-friendly (that is, they meet the needs of a child) latrine slab sizings (a latrine slab is a cover for the latrine pit with a hole to the pit below; users stand on the slab when using the latrine). In Zomerplaag and Moojiman's (2005) guidance for child-friendly hygiene and sanitation facilities in schools, they state that it is not possible to set international standards for facility dimensions because the heights and sizes of children will vary. Instead, they advocate conducting a participatory exercise to determine contextually appropriate dimensions. Whilst this is an ideal approach and should always be conducted, such an exercise may not be possible in the initial (first steps and emergency response) phases of an emergency and the user population may also be frequently changing. As the absence of technical guidance may deter adaptations or result in unsuitable adaptations, we have used the indicative sizings as recommended by UNICEF (2017b), but we encourage the participation of children to improve the designs and to ensure that they are contextually appropriate.

Improving a child's experience of using an emergency toilet

Spaces such as toilets provide child (and adult) users with a range of positive and negative experiences related to colours, smells, shapes and sounds (UNICEF 2012). The guidance suggests a number of ways to improve a child's experience of using emergency toilets, including a higher ratio of facilities to children than for adults to lower waiting-times (Noortgate and Maes 2010; Ferron and Lloyd 2014), enough space for both the child and carer (UNHCR 2018a), open and light structures (Zomerplaag and Moojiman 2005; Deniel 2006) and bright décor (Zomerplaag and Moojiman 2005).

The guidance often assumes that the primary caregiver is the mother, and some guidance recommends positioning gender-neutral children's toilets near to adult female toilets (SuSanA 2012). However, primary caregivers will not always be female, and it may be contextually appropriate to also position gender-neutral children's toilets near to adult male toilets. Yet an 8-year-old girl with a male caregiver may feel uncomfortable using a toilet located close to the adult male toilets and may also feel uncomfortable using a gender-neutral children's toilet located close to the adult female toilets alone and potentially with boys. This emphasises the need for community participation in the design and location of facilities as soon as possible to determine what is culturally and contextually appropriate.

CHILD-SAN: a new disability-inclusive framework for emergency sanitation for children aged five to 11

Using and building upon the existing guidance, we present a new framework for the provision of emergency sanitation for children aged five to 11: CHILD-SAN. CHILD-SAN is an acronym that the WASH sector can use to better provide sanitation facilities for children to use, and includes a number of specific considerations when designing toilets for this age group (Table 3). It is a disability-inclusive framework, that is, it promotes the

Table 3 CHILD-SAN: a new disability-inclusive framework for emergency sanitation for children aged five to 11

C **C**hild participation	- Ensure (a) safe, meaningful and disability-inclusive child participation in emergency WASH preparedness planning and (b) meaningful and disability-inclusive participation in emergency WASH programming from the earliest opportunity that it is safe to do so using existing guidelines (notably O'Kane 2013a) - *See The case for CHILD-SAN facilities section for discussion*
H **H**eights	- Door handles (if being used) should be mounted 800 to 900 mm above the floor (UNICEF 2017a) - Locks (if being used) should be positioned within reach of a child or wheelchair user, at a height of between 680 mm and 800 mm (Save the Children 2013; UNICEF 2017a) - Grab rails on each side of the toilet should be located 300 to 350 mm from the centre of the toilet and between 510mm and 640 mm off the ground (UNICEF 2017a) - Water taps should be positioned within reach of a child or wheelchair user, at a height of between 680 to 800 mm (UNICEF 2017a) - Washbasins (with unobstructed knee clearance for wheelchair users) should be positioned at height of between 650–700 mm and 200 mm deep (UNICEF 2017a)
I user-fr**i**endly	- Consider if (verbal or visual, using simple communication methods) guidance on how to use the toilet needs to be provided - Children are often not prepared to wait, or do not have sufficient bowel or bladder control to wait, and pits may also fill-up relatively more quickly as children drop items down the hole both on purpose and accidentally (Ferron and Lloyd 2014). A ratio of 1 toilet per 20 children is recommended (Noortgate and Maes 2010) - Allow for a spare 0.5 m of depth in the latrine pit size to avoid unpleasant sights and excreta splashing out during use. A pit with a maximum depth of 2 m (an effective depth of 1.5 m) will therefore last for about 2 years if it is used normally by 20 children (an accumulation rate of 0.04 m^3/child) (Noortgate and Maes 2010) - Consider how open the toilet should be. Children, particularly younger children, may prefer an open structure without a door, roof (this may be climate-dependent) or superstructure (Deniel 2006). Such structures alleviate fears of the dark, and younger children also like to imitate and observe others (Zomerplaag and Moojiman 2005) - Provide enough space for two people (for example, a caregiver and child) to use the toilet to enable supervision, help and teaching (UNHCR 2018a), and that accommodates a wheelchair turning radius (1500 mm by 1500 mm) (UNICEF 2017a) - Ensure that doors (if being used) are robust but not too heavy for children to use (Zomerplaag and Moojiman 2005). D-lever door handles are preferred rather than doorknobs (Jones and Wilbur 2014; UNICEF 2017a) - If a toilet seat or chair is being used, grab rails should be provided on each side of the toilet. One should be moveable or foldable on one side to allow for transferring (UNICEF 2017a) - Provide a handle bar and/or handrails to support squatting. Multiple handrails may be needed (vertical, horizontal, various heights) (Noortgate and Maes 2010; Ferron and Lloyd 2014; Jones and Wilbur 2014) - Provide doors with locks and walls that ensure privacy; easy access to water; hooks and shelves; and discrete disposal facilities to aid the changing of soiled menstruation and incontinence products and clothing. Note that the whole collection and disposal chain of soiled items also needs to be considered (Sommer et al. 2017) - Ensure that taps are robust but not too heavy for children to use (Zomerplaag and Moojiman 2005). Large taps with long levers are easier to operate (UNICEF 2017a) - Locate soap for ease of use and where a child with visual or mobility disabilities can easily find/reach it (UNICEF 2017a)
L **L**ocation	- Consider (distance/location) where to safely position gender-neutral and gender-segregated children's toilets that is culturally appropriate for both the child and caregiver
D **D**écor	- Brightly decorated walls can encourage use, and decoration with child-friendly hygiene promotion material can increase awareness at the same time (Zomerplaag and Moojiman 2005) - Decoration can include 'nudges' to use handwashing facilities, for example, footsteps from the toilet to the handwashing facilities - Involving children in decoration can encourage a sense of ownership and deter vandalism (SuSanA 2012)
-	
S **S**caled-down	- Drop-holes should not be so big that a child could fall-in, or be fearful of falling-in: Noortgate and Maes (2010, p.31) provide an indicative diameter of 120 mm - Toilet-seats should be low (350 to 450 mm from floor level) (UNICEF 2017a) or a step provided for children to access the toilet-seat (Banzet 2003) although this may limit access for children with disabilities - Squatting plate dimensions (including the distance between footrests of a squatting platform and the distance from a squatting platform to the wall) should be suitable for a child; indicative dimensions have been provided by Noortgate and Maes (2010, p.31). Smaller squatting plates can be fixed over adult ones (UNICEF 2017b)

Table 3 (continued)

A **A**ccessibility	- Consider accessibility for both the child and caregiver - Position well-lit signs to show the location of the toilets at both adult and child-height, and use simple communication methods, for example, symbols (UNICEF 2017a) - Paths should be wide enough for two people (for example, a caregiver and child) to comfortably pass (Ferron and Lloyd 2014), and ideally 1800 mm wide to allow two wheelchair users to pass (UNICEF 2017a) - Distances and topography of paths must be appropriate for all children and caregivers to navigate - Line paths with painted rocks and provide painted landmark posts to increase visibility (Jones and Wilbur 2014) - Ramps are the preferred solution for access to at least some of the facilities and where used they should have a minimum width of 1000 mm with raised, painted sides (to avoid falling and to increase visibility) and painted handrails recommended for slopes steeper than 1:20 (Jones and Wilbur 2014; UNICEF 2017a) - If there are steps, the step riser height (150 to 170 mm) and step depth (280 to 420 mm) should be suitable for a child, the step surface should be textured to prevent slippage, and a painted handrail provided for visible support (Ferron and Lloyd 2014; Jones and Wilbur 2014) - Entrances should have a minimum width of 800 mm to allow wheelchair access with no thresholds or barriers on the ground (UNICEF 2017a) - Doors (if being used) should open outwards (Jones and Wilbur 2014)
N mo**n**itoring and evaluation	- Ensure the collection of sex-, age- and disability-disaggregated data against contextually appropriate indicators—including the WASH and Child Protection indicators of the Minimum Standards for Child Protection in Humanitarian—to indicate the prevalence of child-friendly facilities and their use - Consider if cleaning and maintenance exploits children and/or discriminates against girls (Save the Children 2013) *See CHILD-SAN: a new disability-inclusive framework for emergency sanitation for children aged five to 11 section for discussion*

construction of toilets that are accessible to all children within this age group, following the principles of universal design (UNICEF 2017a).

An assessment of existing toilets against the CHILD-SAN framework

For a child to use an emergency toilet, they must (a) want to use it and (b) be able to use it. The premise of the CHILD-SAN framework is that it will result in toilets that children aged five to 11 will want, and are able, to use. The assumption is that the collection of usage data will indicate the prevalence of such facilities: usage will be higher if facilities adhere to the recommendations of the CHILD-SAN framework.

The UNHCR monitors and evaluates WASH conditions for all recognised refugee and internally displaced people (IDP) settlements, with initial 'emergency standards' (general guidance is that these are for use up to and including the first 6 months after population movement has stabilised, but definition is context-specific), and longer-term 'post-emergency standards' subsequently (UNHCR 2018b). Additional monitoring frameworks may also be used according to context, for example, to incorporate national standards and/or to include specific field indicators. The UNHCR Core WASH Indicators and associated minimum standards related to toilets are as follows:

- Number of persons per toilet, noting that toilets should be facilities that are cleanable, guarantee privacy and are structurally safe (Emergency standard 1:50/post-emergency standard 1:20 aiming for one latrine per household as soon as possible)
- Percentage of households with household toilet (post-emergency standard 85%)
- Percentage of households reporting defecating in a toilet (emergency standard 60%/post-emergency standard 85%)
- In schools, 50 pupils per toilet on average, being 30 girls per toilet and 60 boys per toilet with additional urinals provided for boys
- In healthcare facilities, 20 outpatients per toilet, and 10 inpatients/beds per toilet (UNHCR 2018b).

Sphere recommends disaggregating data 'to the extent possible and with categories appropriate to the context to understand differences based on sex or gender, age, disability, geography, ethnicity, religion, caste or any other factors that may limit access to impartial assistance … for general data on age use the same cohorts as in national data-collection systems' (Sphere Association 2018, p.12). In the absence of national age cohorts, Sphere recommends the age brackets 0 to 5 years, 6 to 12 years, and 13 to 17 years for children (Sphere Association 2018, p.13). Yet Mazurana et al.'s (2013) review of the collection of sex-and age-disaggregated data (SADD) in humanitarian responses found that the collection of SADD was 'extremely limited, ad hoc and sporadic' (p.S77). Further, even when SADD is collected, the majority of those interviewed believed that 'field officers do not necessarily know what to do with it' (Mazurana et al. 2013, p.S78). House (2019) also found that in Cox's Bazar, Bangladesh, although the Gender in Humanitarian Action (GiHA)

cross-sectoral group had been encouraging the collection of SADD, it had overlooked data on disability.

Mazurana et al.'s and House's findings were reflected in the lack of data we found on the provision and use of toilets by children aged five to 11. Although anecdotal evidence of CHILD-SAN facilities (or the lack thereof) was noted, no quantitative data was found. Positive reports, *with the CHILD-SAN attributes acknowledged noted in**bold**where sufficient detail is provided*, included the following:

- In Rwanda in 1994, open child latrines with smaller squat holes were provided in IDP camps to be used by children aged two and older. Similar latrines was used in IDP camps in Uganda in 2006 (Harvey 2007) (CH**I**LD-**S**AN)
- Dropholes with dedicated cubicles for children were installed in the Petion Ville Golf Course camp in Port-au-Prince, Haiti (Bastable and Lamb 2012) (CHILD-SAN unknown)
- Yates et al. (2018) conducted a systematic review on the efficacy and effectiveness of short-term WASH interventions in emergency responses in low- and middle-income countries. The review found that when designing latrines, specific consideration for women and vulnerable populations including children were documented in South Sudan, India, and Liberia. This led to more appropriate latrine designs with marginal additional costs (CHILD-SAN unknown)
- In the informal tented settlements of the Bekaa Valley, Lebanon, locks at child-height were added to the latrines (Jabbar 2018) (C**H**ILD-SAN)
- The UN Children's Fund (UNICEF) is trialling an accessible latrine slab for emergencies in Angola with users to include children (UNICEF 2017b) (CH**I**LD-**S**AN).

Negative anecdotes, *with the CHILD-SAN attributes not acknowledged noted in**bold**where sufficient detail is provided*, included:

- In the Bahn refugee camp in Nimba, Liberia, 700 children aged five to ten were identified, but the WASH programme evaluator had no information that their specific sanitation needs were addressed outside of the schools (Visser 2012) (CHILD-SAN unknown)
- In Ferron and Lloyd's (2014) study of emergency sanitation for children, 29% of respondents had provided child-friendly toilets in schools, but only 16% had provided child-friendly toilets in community settings. Whereas child-friendly WASH facilities were sometimes provided in health centres and most often provided in child-friendly spaces (CFSs, safe places for children). Further, informants noted that the needs of different age groups of children were not considered (CHILD-SAN unknown)
- In the province of Leyte in the Philippines post-typhoon Haiyan, children aged between 2 and 7 years old reported finding ceramic bowl toilets difficult to use and were sometimes afraid of using the 'Comfort Rooms' due to the lack of handrails, an unfamiliarity with using a ceramic bowl toilet, not liking the feel of the ceramic bowl toilet and/or a fear of sitting on it, and a fear that the toilet hole was too big (Denis 2015) (CH**I**LD-**S**AN)
- In Cox's Bazaar, Bangladesh, women reported giving their children less food to avoid using the latrine at night (Farrington 2018) (CHILD-S**A**N)
- Also in Cox's Bazar, House (2019) noted that, in one CFS visited that although the toilet units themselves were well designed for children, the entrances to the male and female toilet doors were situated together behind the same wall without a division, so that males had to walk by the female door to access the male urinals (CHI**L**D-SAN)
- Bedwetting by children has been noted by NGO workers in refugee camps (Veneme 2015; Farrington 2019; House 2019). Whilst some children may be experiencing urinary incontinence (the involuntary leakage of urine during the day and/or at night), some instances may be due to a reluctance to use the existing facilities (social incontinence) (CHILD-SAN unknown).

The lack of quantitative data can be attributed to a multitude of reasons, not least the challenges of collecting data in emergency contexts and the prioritisation of response activities (Yates et al. 2018). But as Mazurana et al. (2013, p.S79) concluded, 'the additional time and resources needed to (collect SADD) are justified by the improvements in programming and by avoiding costly programme failures due to errors in targeting and design.'

We reiterate Mazurana et al.'s (2013) recommendation that SADD is collected in all phases of an emergency to inform the response and further expand this to include data disaggregated by disability (assessed using the Washington Group/UNICEF child functioning question set) as recommended by the Age and Disability Consortium (ADCAP) (Age and Disability Consortium 2018) (Table 3). Collecting data to determine the percentage of households reporting defecation in a toilet disaggregated by sex, age and disability would indicate the prevalence of child-friendly facilities and their use, the assumption

being that usage would be higher if facilities addressed the CHILD-SAN recommendations. It is also recommended that the WASH and Child Protection indicators and targets of the Minimum Standards for Child Protection in Humanitarian Action are adapted to the context and used in conjunction with the Sphere standards as soon as possible (Table 3). Those related to toilets are as follows:

- Percentage of WASH projects where child safety and wellbeing are reflected in the initial risk assessment, design, monitoring and evaluation framework (Target 100%)
- Percentage of surveyed sites with separated communal facilities (toilet and bathing facilities) for girls/women and boys/men (Target 100%)
- Percentage of surveyed sites with communal facilities that meet 90% of safety criteria (Target 100%, safety criteria defined using in-country checklist)
- Percentage of schools, play areas, health centres etc., that include child-appropriate WASH facilities (Target 100%, child-appropriate defined in-country)
- Percentage of accessible WASH facilities (for children with disabilities, adolescent girls) (Target 100%) (The Alliance for Child Protection in Humanitarian Action 2019)

The recommendation to consistently use known standards in monitoring frameworks aligns with the initial findings of the Quality Assurance and Accountability Project (QAAP), which is an ongoing Global WASH cluster initiative to determine how best to measure quality in humanitarian WASH responses (Brown 2019).

The case for CHILD-SAN facilities

If there are many reasons why child-friendly toilets for children aged five to 11 are not always provided, and why data disaggregated by sex, age and disability is not always collected and/or actioned to determine if they are being provided and used, there are just as many reasons advocating for CHILD-SAN facilities. The first is the sheer number of beneficiaries: in 2019, 1 in 5 known persons of concern were aged between 5 and 11 years of age (UNHCR 2020).

If there are facilities available but a child does not want to or cannot use them, they may choose to urinate and defecate elsewhere instead, for example, outside or within a shelter. House (2019) found that some children in the Cox's Bazar refugee camps (Bangladesh) were fearful of using the toilets, but urinating or defecating elsewhere may also expose the child to risks of injuries, abuse and/or exploitation (UNICEF 2017a). Habitually delaying urination until a suitable place is found also increases the risk of developing urinary incontinence (the involuntary leakage of urine) due to bladder dysfunction (Zhou et al. 2019). A child may also urinate or defecate on themselves instead of using what is felt to be an unsuitable toilet, which is known as 'social incontinence' (Ryan 2018). Children that wet themselves can suffer from incontinence associated dermatitis (IAD; similar to nappy rash), skin infections, pressure sores, urinary tract infections and dehydration (if fluid restriction is used as a management strategy) (Rosato-Scott et al. 2019). The social and emotional impact on their lives and their carers' lives can also be significant: any resultant personal embarrassment and shame, or social ostracism (for example, due to smell) can prevent participation in programming, education and social activities (Hafskjold et al. 2016).

There are also legal arguments. The Convention on the Rights of the Child states that 'children have the right to … a clean and safe environment' (Article 24) (UN 1990). Decades later, the Human Rights to Water and Sanitation (HRWS) were recognised by the UN General Assembly on July 28, 2010 (Resolution 64/292), and recognised in international law by the Human Rights Council's Resolution 15/9 on September 30, 2010 (United Nations 2010a, b). Sanitation was later recognised as a distinct and separate human right by the UN General Assembly on December 17, 2015 (Resolution 70/169), which stated that 'the human right to sanitation entitles everyone, without discrimination, to have physical and affordable access to sanitation, in all spheres of life, that is safe, hygienic, secure, socially and culturally acceptable and that provides privacy and ensures dignity' (United Nations 2015).

To achieve this human right, the international community are striving to attain SDG Target 6.2, which aims to 'achieve access to adequate and equitable sanitation and hygiene for all … paying special attention to the needs of women and girls and those in vulnerable situations' by 2030 (United Nations 2016). Given the broad definition of sanitation that we have used, the provision of CHILD-SAN facilities would support the attainment of the Human Right to Sanitation for children aged five to 11.

Humanitarian actors also have moral obligations—the 'humanitarian imperative'—to take action 'to prevent or alleviate human suffering arising out of disaster or conflict' (Sphere Association 2018, p.28). This is enshrined in the Humanitarian Charter, which all agencies that endorse Sphere commit to (Sphere Association 2018). The provision of CHILD-SAN facilities acknowledges the right to live with dignity that the Humanitarian Charter advocates.

How the WASH sector can improve the provision of CHILD-SAN facilities

Article 12 of the UN CRC states the right of children to be heard and to be taken seriously, and is one of the four general principles of the Convention, alongside the right to non-discrimination, the right to life and development, and the primary consideration of the child's best interests (UN 1990). Further, General Comment Number 12 states that this right 'does not cease in situations of crisis or in their aftermath' (Paragraph 125, United Nations Committee on the Rights of the Child 2009).

There is much literature on the value of child participation, summarised by the General Comment as 'helping children to regain control over their lives, contributing to rehabilitation, developing organisational skills and strengthening a sense of identity' with the caveat that 'care needs to be taken to protect children from exposure to situations that are likely to be traumatic or harmful' (Paragraph 125, United Nations Committee on the Rights of the Child 2009).

There is also much written on (a) the basic requirements of the implementation of a child's right to be heard, the foundational text being the Committee on the Rights of the Child's nine basic requirements of meaningful child participation (Paragraph 134, United Nations Committee on the Rights of the Child 2009), and (b) guidelines on how best to achieve child participation in humanitarian programming (notably O'Kane 2013a).

Yet despite many WASH sector-specific guidelines recommending the participation of children in the design of emergency sanitation facilities—most recently Oxfam's Sani Tweaks series (Oxfam 2018)—and there being 'how to' materials available, few examples were found by either our systematic review of publications or Ferron and Lloyd's study on emergency WASH for children of all ages (Ferron and Lloyd 2014). This gives rise to the question: why are not children, including children with disabilities, being pro-actively involved and invited to participate in WASH programme design?

In 2017, the Humanitarian Innovation Fund (HIF) launched a WASH Innovation Challenge to pilot rapid community engagement for user-centred sanitation. In response, Eclipse Experience (Eclipse) and Save the Children developed a User-Centred Community Engagement (UCCE) methodology to improve the design of latrines and handwashing facilities for users including children aged 5 to 12 years (Eclipse Experience 2019). Oxfam's evaluation of the four projects implemented under the HIF challenge (two of which, in Bangladesh and Iraq, were implemented by Eclipse and Save the Children) found that time can be made to consult in a meaningful way even in short projects and that the use of well-designed, tightly focused surveys with adequate representative sampling can find out much, quickly (Sandison 2017). Challenges for rapid, user-centred community engagement were also noted however, including that when there is restricted project scope at the project proposal and design stage, the possibilities of user-centred design are limited, and that the design of facilities only does not address users' further engagement in the implementation and maintenance of the infrastructure provided (Sandison 2017).

Oxfam concluded that the main potential of greater community engagement during an emergency response may be when projects move out of the acute response phases into the consolidation (or stabilisation) phase. It was therefore suggested that the initial infrastructure provided is used as a prototype on which the users can provide feedback, noting that this initial infrastructure should always incorporate the design fundamentals of access, dignity, privacy and safety, and be adaptable to ensure that it can become more sustainable (SuSanA 2012; Sandison 2017). O'Kane's (2013b) review of child participation in humanitarian programming similarly found that there are significant constraints to the safe and meaningful participation of children in the very early stages of an emergency response, and that there are more opportunities to strengthen children's participation in emergency preparedness and once the acute response phases have passed.

However, House (2019) found that the danger of relegating issues to 'when we have time' is that they will never be done and believes that even the simple consultation of a few people representing different groups can and should start right from the beginning of an emergency as this can lead to better initial prototypes that can then be improved through more involved participation and feedback.

CHILD-SAN therefore recommends (a) safe, meaningful and disability-inclusive child participation in emergency WASH preparedness planning, and (b) meaningful and disability-inclusive participation in emergency WASH programming from the earliest opportunity that it is safe to do so, using existing guidelines on how best to achieve child participation in humanitarian programming (notably O'Kane 2013a) (Table 3). For example, ensuring field staff have training and skills to communicate with children, including activities and budgets for children's participation in plans, and reporting against the global children's participation indicator (children's participation that is voluntary, safe and inclusive) (O'Kane 2013a). Such an approach will require commitment from 'senior to field levels (and) across agencies' (House 2019). The

dissemination of the CHILD-SAN framework to WASH practitioners at all levels aims to raise the profile of the needs of children aged 5–11, which is not prominent in any existing guidance; and it is hoped will encourage an increase in awareness of the needs and commitment by providing an easy-to-use reminder of the key tenets of providing emergency sanitation for children aged five to 11, with associated references when further detail is needed.

Conclusion

We have critically reviewed existing guidance for the provision of emergency sanitation for children aged five to 11 and subsequently presented a new disability-inclusive framework (CHILD-SAN) that the WASH sector can use to better provide sanitation facilities for children. The framework recommends (a) safe and meaningful child participation in emergency WASH preparedness planning and emergency WASH programming as a means to develop contextually appropriate facilities, (b) specific design considerations for child-friendly toilets and (c) the collection of sex-, age- and disability-disaggregated data against contextually appropriate indicators to determine the prevalence of child-friendly facilities and their use.

We believe that the implementation of CHILD-SAN would contribute to the WASH sector's aims of achieving universal sanitation and maximising opportunities for good health, dignity, comfort and safety for all. Facilities that do not adhere to the recommendations of the CHILD-SAN framework are known to adversely impact the health, comfort and safety of children. Less is known about the impact on dignity, and our next steps will include research to understand the social and emotional impacts of social incontinence on children and their caregivers.

Abbreviations

ADCAP: Age and Disability Consortium; CCCs: Core Commitments for Children in Humanitarian Action; CFS: Child-friendly space; CRC: Convention on the Rights of the Child; GiHA: Gender in Humanitarian Action; HIF: Humanitarian Innovation Fund; HRP: Humanitarian Response Plan; HRWS: Human Rights to Water and Sanitation; IAD: Incontinence-associated dermatitis; IDP: Internally displaced people; OCHA: United Nations Office for the Coordination of Humanitarian Affairs; QAAP: Quality Assurance and Accountability Project; SADD: Sex-and Age-Disaggregated Data; SDGs: Sustainable Development Goals; UCCE: User-Centred Community Engagement; UN: United Nations; UNICEF: United Nations Children's Fund; UNHCR: United Nations High Commissioner for Refugees; WASH: Water, Sanitation and Hygiene; WHO: World Health Organization.

Supplementary Information

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Additional file 1: Table 1. Classification of publications as meeting Criterion 2a and/or Criterion 2b.

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Authors' contributions

CRS initiated the report; conducted the systematic review and analysis; wrote the first draft of the manuscript; and updated the manuscript for review comments. DJB provided guidance on the overall study. DJB and BEE provided review comments; and read and approved the final manuscript. The author(s) read and approved the final manuscript.

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Declarations

Competing interests

The authors declare that they have no competing interests.

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References

Age and Disability Consortium (2018) Humanitarian inclusion standards for older people and people with disabilities. https://reliefweb.int/report/world/humanitarian-inclusion-standards-older-people-and-people-disabilities. Accessed 14 Nov 2018

Banzet J (2003) Towards child-friendly latrines in Viet Nam. Waterfront 16:18–19.

Bastable A, Lamb J (2012) Innovative designs and approaches in sanitation when responding to challenging and complex humanitarian contexts in urban areas. Waterlines 31. https://doi.org/10.3362/1756-3488.2012.007

Behnke N, Cronk R, Snel M et al (2018) Improving environmental conditions for involuntarily displaced populations: water, sanitation, and hygiene in orphanages, prisons, and refugee and IDP settlements. J Water Sanit Hyg Dev:1–7. https://doi.org/10.2166/washdev.2018.019

Brown J (2019) Oxfam views & voices: three things we've learned about measuring quality in humanitarian WASH responses. https://views-voices.oxfam.org.uk/2019/07/measuring-quality-wash-responses/. Accessed 8 Aug 2019

Deniel K (2006) Children's sanitation in emergencies. Waterlines 24:28. https://doi.org/10.3362/0262-8104.2006.012

Denis J (2015) Sanitation practices for infants and children in emergencies. Dissertation, Cranfield University, Cranfield

Eclipse Experience (2019) User-centred community engagement. http://www.eclipse-experience.com/user-centred-community-engagement. Accessed 8 Mar 2019

Farrington M (2018) Women's Social Architecture Project: phase 1 final report, Cox's Bazaar https://oxfam.app.box.com/s/gmiiqfdn7ntbxeve7fiklywfitnkcjy/file/384891125807. Accessed 11 Dec 2018
Farrington M (2019) Conversation with Claire Rosato-Scott 20 February 2019
Ferron S, Lloyd A (2014) Emergency WASH for children. https://www.elrha.org/wp-content/uploads/2015/02/2014-10-11-Emergency-WASH-for-Children-Final.pdf. Accessed 1 Nov 2018
Gensch R, Jennings A, Renggli S, Reymond P (2018) Compendium of sanitation technologies in emergencies. https://www.eawag.ch/fileadmin/Domain1/Abteilungen/sandec/schwerpunkte/sesp/Emergencies/compendium_emergencies.pdf. Accessed 22 Feb 2019
Global WASH Cluster (2019) Global WASH cluster annual meeting report. Global WASH Cluster, Geneva
Groupe URD (2019) Analysis of the capacity of the WASH sector. https://www.urd.org/en/publication/analysis-of-the-capacity-of-the-wash-sector-june-2019/. Accessed 1 Aug 2019
Hafskjold B, Pop-Stefanija B, Giles-Hansen C et al (2016) Taking stock: incompetent at incontinence – why are we ignoring the needs of incontinence sufferers? Waterlines 35. https://doi.org/10.3362/1756-3488.2016.018
Harvey P (2007) Excreta disposal in emergencies. https://wedc.ac.uk/publications/. Accessed 7 Mar 2019
House S (2019) Strengthening the humanity in humanitarian action in the work of the WASH sector in the Rohingya response. https://www.humanitarianlibrary.org/resource/strengthening-humanity-humanitarian-action-work-wash-sector-rohingya-response-gender-gbv. Accessed 25 Mar 2019
Jabbar GA (2018) Gender-based violence in relation to water, sanitation and hygiene in the informal tented settlements of the Bekaa Valley, Lebanon. Dissertation, University of Leeds, Leeds
Jones H, Wilbur J (2014) Compendium of accessible WASH technologies. https://washmatters.wateraid.org/publications/compendium-of-accessible-wash-technologies. Accessed 17 May 2017
Langford M, Bartram J, Roaf V (2017) The human right to sanitation. In: Langford M, Russell AFS (eds) The human right to water: theory, practice and prospects. Cambridge University Press, Cambridge, pp 345–395
Mazurana D, Benelli P, Walker P (2013) How sex-and age-disaggregated data and gender and generational analyses can improve humanitarian response. Disasters 37:S68–S82. https://doi.org/10.1111/disa.12013
Moher D, Liberati A, Tetzlaff J et al (2009) Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. PLoS Med 6:e1000097. https://doi.org/10.1371/journal.pmed.1000097
Noortgate JVD, Maes P (2010) Public Health Engineering in precarious situations. http://refbooks.msf.org/msf_docs/en/public_health/public_health_en.pdf. Accessed 18 Nov 2018
O'Kane C (2013a) Guidelines for children's participation in humanitarian programming. https://reliefweb.int/sites/reliefweb.int/files/resources/Children_Participation_Humanitarian_Guidelines.pdf. Accessed 31 Mar 2019
O'Kane C (2013b) Review of children's participation in humanitarian programming. https://www.alnap.org/system/files/content/resource/files/main/children-participation-humanitarian-review.pdf. Accessed 18 Nov 2018
OCHA (2018) Global humanitarian overview 2019. https://www.unocha.org/global-humanitarian-overview-2019. Accessed 10 Jan 2019
OCHA (2019) Humanitarian response plan. https://www.humanitarianresponse.info/en/operations/nigeria/humanitarian-response-plan. Accessed 18 July 2019
OCHA (2020) Global humanitarian overview 2021. https://www.unocha.org/global-humanitarian-overview-2021. Accessed 8 Feb 2021
Oxfam (2013) Oxfam Minimum Requirements for WASH Programmes (MR-WASH). https://policy-practice.oxfam.org.uk/publications/oxfam-minimum-requirements-for-wash-programmes-mr-wash-300134. Accessed 18 Nov 2018
Oxfam (2018) Sani Tweaks. Best practices in sanitation. www.oxfam.org.uk/sanitweaks. Accessed 31 Mar 2019
Rosato-Scott CA, Giles-Hansen C, House S, et al (2019) Guidance on supporting people with incontinence in humanitarian and low- and middle-income contexts (LMICs). https://wash.leeds.ac.uk/wp-content/uploads/sites/45/2019/08/Guidance-document_August-2019_Version_1.pdf. Accessed 16 Aug 2019
Ryan F (2018) 'It's horrifically painful': the disabled women forced into unnecessary surgery. https://www.theguardian.com/society/2018/aug/06/disabled-women-surgery-catheter-accessible-toilets. Accessed 27 Feb 2019
Sandison P (2017) We're listening: an evaluation of user-centred community engagement in emergency sanitation. https://oxfamilibrary.openrepository.com/bitstream/handle/10546/620617/gd-listening-community-engagement-emergency-sanitation-050219-en.pdf?sequence=1&isAllowed=y. Accessed 15 Feb 2019
Save the Children (2013) WASH for children in emergencies. https://www.elrha.org/wp-content/uploads/2015/02/Annex-E-Hygiene_Promotion_September_Newsletter_2013.pdf. Accessed 10 Jan 2019
Sommer M, Schmitt M, Clatworthy D (2017) A toolkit for integrating Menstrual Hygiene Management (MHM) into humanitarian response. https://www.humanitarianlibrary.org/resource/toolkit-integrating-menstrual-hygiene-management-mhm-humanitarian-response. Accessed 26 Feb 2021
Sphere Association (2018) The sphere handbook: humanitarian charter and minimum standards. www.practicalactionpublishing.org/sphere. Accessed 14 Nov 2018
SuSanA (2012) Sustainable sanitation for emergencies and reconstruction situations. www.humanitarianreform.org. Accessed 6 Mar 2019
Tanner S, O'Connor M (2017) A safe place to shine. Creating opportunities and raising voices of adolescent girls in humanitarian settings. https://www.rescue.org/sites/default/files/document/2248/irccompassglobalreport.pdf. Accessed 14 Mar 2019
The Alliance for Child Protection in Humanitarian Action (2019) Table of indicators: minimum standards for child protection in humanitarian action, 2019 edition. https://alliancecpha.org/en/CPMS_Table_Indicators. Accessed 10 Feb 2020
UNHCR (2018a) UNHCR WASH manual. Practical guidance for refugee settings. http://wash.unhcr.org/unhcr-wash-manual-for-refugee-settings/. Accessed 14 Nov 2018
UNHCR (2018b) UNHCR Core WASH indicators. https://wash.unhcr.org/unhcr-wash-standards-and-indicators-for-refugee-settings/. Accessed 25 Jan 2019
UNHCR (2020) UNHCR population statistics. https://www.unhcr.org/refugee-statistics/download/?url=E1ZxP4. Accessed 8 Feb 2021
UNICEF (2010) Core commitments for children in humanitarian action. www.unicef.org. Accessed 30 Nov 2018
UNICEF (2012) Water, sanitation and hygiene (WASH) in schools. UNICEF, New York
UNICEF (2017a) Guidance: including children with disabilities in humanitarian action – WASH. https://training.unicef.org/disability/emergencies/downloads/UNICEF_WASH_English.pdf. Accessed 22 Feb 2019
UNICEF (2017b) UNICEF target product profile: accessible latrine slab for emergencies. https://www.unicef.org/supply/files/2017.04.05_Accessible_Latrine_Slab_TPP_v2.2.pdf. Accessed 21 Feb 2019
UNICEF (2018) Humanitarian Action for Children 2018. https://www.unicef.org/eca/reports/unicefhumanitarian-action-children-2018. Accessed 14 Mar 2019
United Nations (1990) The United Nations convention on the rights of the child. https://www.unicef.org.uk/what-we-do/un-convention-child-rights/. Accessed 7 Nov 2018
United Nations (2010a) UNGA Resolution 64/292. The human right to water and sanitation. https://undocs.org/en/A/RES/64/292. Accessed 17 Mar 2019
United Nations (2010b) HRC Res 15/9. Human rights and access to safe drinking water and sanitation. https://undocs.org/A/HRC/RES/15/9. Accessed 17 Mar 2019
United Nations (2015) UNGA Resolution 70/169. The human rights to safe drinking water and sanitation. https://undocs.org/en/A/RES/70/169. Accessed 17 Mar 2019
United Nations (2016) Sustainable development goal 6. https://sustainabledevelopment.un.org/sdg6. Accessed 15 Nov 2018
United Nations Committee on the Rights of the Child (2009) General comment on A12 Right to Be Heard. http://www.crae.org.uk/publications-resources/uncrc-general-comment-on-right-to-be-heard-(article-12)/. Accessed 31 Mar 2019
Veneme V (2015) The unlikely sanitary pad missionary. https://www.bbc.co.uk/news/magazine-34925238. Accessed 8 May 2019

Visser M (2012) External evaluation WASH provision in Bahn refugee camp in Nimba, Liberia. https://www.alnap.org/system/files/content/resource/files/main/acf-bahn-camp-liberia-wash-evaluation-report.pdf. Accessed 7 Mar 2019

WHO (2006) Constitution of the World Health Organisation. WHO, Geneva. Accessed 31 Jan 2019

WHO (2008) Managing WHO humanitarian response in the field. https://www.who.int/hac/techguidance/tools/full_manual.pdf. Accessed 14 Nov 2018

WHO (2018) Health topics: sanitation. https://www.who.int/topics/sanitation/en/. Accessed 17 Mar 2019

Yates T, Allen Vujcic J, Leandre Joseph M et al (2018) Efficacy and effectiveness of water, sanitation, and hygiene interventions in emergencies in low-and middle-income countries: a systematic review. Waterlines 37. https://doi.org/10.3362/1756-3488.17-00016

Zhou F, Xue K, Liu Y et al (2019) Toileting behaviors and factors associated with urinary incontinence in college-aged female students in China. Int Urogynecol J. https://doi.org/10.1007/s00192-019-04043-3

Zomerplaag J, Moojiman A (2005) Child-friendly hygiene and sanitation facilities in schools: indispensable to effective hygiene education. https://www.ircwash.org/sites/default/files/Zomerplaag-2005-Child.pdf. Accessed 10 Mar 2019

Publisher's Note

A5 Manuscript 1 supplementary material: Classification of publications as meeting Criterion 2a and/or Criterion 2b

Table 8 Classification of publications as meeting Criterion 2a and/or Criterion 2b

Publication	Guidance (Criterion 2a)	Reported (Criterion 2b)	Location of reported example	Citation
Action Against Hunger International (2017) WASH' Nutrition: A practical guidebook on increasing nutritional impact through integration of WASH and nutrition programmes.	X			(Action Against Hunger International, 2017)
Action contra la Faim (2005) Water, sanitation and hygiene for populations at risk.	X			(Action contre la Faim, 2005)
Age and Disability Consortium (2018) Humanitarian inclusion standards for older people and people with disabilities.	X			(Age and Disability Consortium, 2018)
Baghri S, Wilson T (2004) Plan's approach to water and environmental sanitation.	X			(Baghri and Wilson, 2004)
Bangladesh Government (2017) Operational Guidelines for WASH in Emergencies – Bangladesh.	X			(Bangladesh Government, 2017)
Banzet J (2003) Towards child-friendly latrines in Viet Nam.	X			(Banzet, 2003)
Bastable A, Lamb J (2012) Innovative designs and approaches in sanitation when responding to challenging and complex humanitarian contexts in urban areas.		X	Haiti	(Bastable and Lamb, 2012)

Bastable A, Russell L, Gb O (2013) Gap Analysis in Emergency Water, Sanitation and Hygiene Promotion.	X			(Bastable et al., 2013)
Behnke N, Cronk R, Snel M, et al (2018) Improving environmental conditions for involuntarily displaced populations: water, sanitation, and hygiene in orphanages, prisons, and refugee and IDP settlements.	X			(Behnke et al., 2018)
Brown J, Cavill S, Cumming O, Jeandron A (2012) Water, sanitation, and hygiene in emergencies: Summary review and recommendations for further research.	X			(Brown et al., 2012)
Child Protection Working Group (2012) Minimum standards for child protection in humanitarian action Updated to: The Alliance for Child Protection in Humanitarian Action (2019) Minimum Standards for Child Protection in Humanitarian Action, 2019 Edition. The Alliance for Child Protection in Humanitarian Action (2019) Table of Indicators: Minimum Standards for Child Protection in Humanitarian Action, 2019 Edition.	X			(The Alliance for Child Protection in Humanitarian Action 2019a) (The Alliance for Child Protection in Humanitarian Action 2019b)
Deniel K (2006) Children's sanitation in emergencies.	X			(Deniel, 2006)
Denis J (2015) Sanitation practices for infants and children in emergencies.		X	Philippines	(Denis, 2015)

Eclipse Experience (2019) User-Centred Community Engagement.		X	Bangladesh Iraq	(Eclipse Experience, 2019c)
Farrington, M (2018) Women's Social Architecture Project: Phase 1 Final Report. Cox's Bazaar, Bangladesh.		X	Bangladesh	(Farrington 2018)
Ferron S, Lloyd A (2014) Emergency WASH for children.	X	X	Bangladesh Ethiopia	(Ferron and Lloyd, 2014)
Gensch R, Jennings A, Renggli S, Reymond P (2018) Compendium of Sanitation Technologies in Emergencies.	X			(Gensch et al., 2018)
Gustave YG (2011) Sanitation solutions for a refugee camp: Field trial of sanitation for the vulnerable.		X	Liberia	(Gustave, 2011)
Harvey P (2007) Excreta Disposal in Emergencies.	X	X		(Harvey, 2007)
House S (2019) Strengthening the humanity in humanitarian action in the work of the WASH sector in the Rohingya response		X	Bangladesh	(House, 2019)
IASC (2006) Women, girls, boys and men: different needs - equal opportunities. Gender handbook for humanitarian action.	X			(IASC, 2006)
Jabbar GA (2018) Gender-based violence in relation to water, sanitation and hygiene in the informal tented settlements of the Bekaa Valley, Lebanon.		X	Lebanon	(Jabbar, 2018)
Johannessen A (2011) Identifying gaps in emergency sanitation. Design of new kits to	X			(Johannessen, 2011)

increase effectiveness in emergencies.				
Johns Hopkins Bloomberg School of Public Health, International Federation of Red Cross and Red Crescent Societies (2008) The John Hopkins and Red Cross Red Crescent Public health guide in emergencies.	X			(Johns Hopkins Bloomberg School of Public Health and International Federation of Red Cross and Red Crescent Societies, 2008)
Jones H, Wilbur J (2014) Compendium of accessible WASH technologies.	X			(Jones and Wilbur, 2014)
Langford M, Bartram J, Roaf V (2017) The Human Right to Sanitation.	X			(Langford et al., 2017)
Mazurana D, Benelli P, Gupta H, Walker P (2011) Sex and Age Matter: Improving Humanitarian Response in Emergencies.	X			(Mazurana et al., 2011)
Mazurana D, Benelli P, Walker P (2013) How sex-and age-disaggregated data and gender and generational analyses can improve humanitarian response.	X			(Mazurana et al., 2013)
Noortgate J V D, Maes P (2010) Public Health Engineering in Precarious Situations.	X			(Noortgate and Maes 2010)
O'Kane C (2013a) Guidelines for Children's Participation in humanitarian programming.	X			(O'Kane, 2013b)
O'Kane C (2013b) Review of children's participation in humanitarian programming.	X			(O'Kane, 2013a)
Obani P (2017) 183. Inclusiveness in humanitarian action — access to water, sanitation	X			(Obani, 2017)

& hygiene in focus.				
OCHA (2018) Global Humanitarian Overview 2019. Updated to: OCHA (2018) Global Humanitarian Overview 2021.	X			(OCHA 2019) (OCHA 2020)
Oxfam (2012) Working with Children in Humanitarian WASH Programmes.	X			(Oxfam, 2012)
Oxfam (2013) Oxfam Minimum Requirements for WASH Programmes (MR-WASH).	X			(Oxfam, 2013)
Oxfam (2018) Sani Tweaks. Best practices in sanitation.	X			(Oxfam, 2018)
Oxfam International, WEDC (2018) Shining a Light: How lighting in or around sanitation facilities affects the risk of gender-based violence in camps.	X			(Oxfam International and WEDC, 2018)
Pink R (2012) Child rights, right to water and sanitation, and human security.	X			(Pink, 2012)
REACH Initiative (2015) Comprehensive Child Focused Assessment. Azraq Refugee Camp.		X	Jordan	(REACH Initiative, 2015)
REACH Initiative (2018) Water, Sanitation and Hygiene Follow-up Assessment Monsoon Season (August-October 2018).		X	Bangladesh	(REACH Initiative, 2018)
Rouse R, Reed R (2013) Solid waste management in emergencies.	X			(Rouse and Reed 2013)
Sandison P (2017) We’re Listening: An evaluation of user-centred community engagement in emergency sanitation.		X	Bangladesh Iraq	(Sandison, 2017)
Save the Children (2013) WASH for Children in Emergencies.	X			(Save the Children, 2013)

Sphere Association (2018) The Sphere Handbook: Humanitarian Charter and Minimum Standards.	X			(Sphere Association, 2018)
SuSanA (2012) Sustainable sanitation for emergencies and reconstruction situations.	X			(SuSanA, 2012)
Tanner S, O'Connor M (2017) A safe place to shine. Creating opportunities and raising voices of adolescent girls in humanitarian settings.	X			(Tanner and O'Connor, 2017)
Toms C, Macleod H (2006) World Vision International Children in Emergencies Manual.	X			(Toms and Macleod, 2006)
UNHCR (2015) Design Guidelines for Emergency Toilets in Refugee Settings.	X			(UNHCR, 2015)
UNHCR (2018a) Global Trends. Forced Displacement in 2017.	X			(UNHCR, 2018a)
UNHCR (2018b) UNHCR Core WASH Indicators.	X			(UNHCR, 2018b)
UNHCR (2018c) UNHCR Population Statistics. Updated to: UNHCR (2020) UNHCR Population Statistics.	X			(UNHCR, 2021) (UNHCR 2020)
UNHCR (2018d) UNHCR WASH Manual. Practical Guidance for Refugee Settings.	X			(UNHCR, 2018c)
UNICEF (2005) Emergency Field Handbook. A guide for UNICEF staff.	X			(UNICEF, 2005)
UNICEF (2010) Core Commitments for Children in Humanitarian Action.	X			(UNICEF, 2010)
UNICEF (2017a) UNICEF Target Product Profile: Accessible Latrine Slab for Emergencies.	X	X	Angola	(UNICEF, 2017a)
UNICEF (2017b) Accessible latrine slab for emergencies: Q&As.	X			(UNICEF, 2017b)

UNICEF (2017c) Guidance: Including children with disabilities in humanitarian action – WASH.	X			(UNICEF, 2017c)
UNICEF (2018) Humanitarian Action for Children 2018.	X			(UNICEF, 2018)
United Nations (1990) The United Nations Convention on the Rights of the Child.	X			(United Nations, 1990)
United Nations (2010a) UNGA Resolution 64/292. The human right to water and sanitation.	X			(United Nations 2010a)
United Nations (2010b) HRC Res 15/9. Human rights and access to safe drinking water and sanitation.	X			(United Nations 2010b)
United Nations (2015) UNGA Resolution 70/169. The human rights to safe drinking water and sanitation.	X			(United Nations, 2015)
United Nations (2016) Sustainable Development Goal 6.	X			(United Nations, 2016)
United Nations Committee on the Rights of the Child (2009) General Comment on A12 Right to Be Heard.	X			(United Nations Committee on the Rights of the Child, 2009)
Visser M (2012) External Evaluation WaSH Provision in Bahn Refugee Camp in Nimba, Liberia.		X	Liberia	(Visser, 2012)
WHO (2008) Managing WHO Humanitarian Response in the Field.	X			(WHO, 2008)
WHO (2018) Health topics: Sanitation.	X			(WHO, 2018b)

Yates T, Allen Vujcic J, Leandre Joseph M, et al (2018) Efficacy and effectiveness of water, sanitation, and hygiene interventions in emergencies in low-and middle-income countries: a systematic review.		X	India Liberia South Sudan	(Yates et al., 2018)
Zakaria F, Muratbegovic A, Brdjanovic D, et al (2017) Evaluation of a smart toilet in an emergency camp.		X	Philippines	(Zakaria et al., 2017)
Zomerplaag J, Moojiman A (2005) Child-Friendly Hygiene and Sanitation Facilities in Schools: Indispensable to effective hygiene education.	X			(Zomerplaag and Mooijman, 2005)

The 69 publications that met Criterion 2 were classified as either providing guidance on (Criterion 2a) or reporting on (Criterion 2b) the provision of emergency sanitation for children aged five to 11.

References

Action Against Hunger International (2017) WASH' Nutrition: A practical guidebook on increasing nutritional impact through integration of WASH and nutrition programmes. https://www.actionagainsthunger.org.uk/sites/default/files/publications/action_against_hunger_wash_nutrition_guidebook.pdf. Accessed 30 Nov 2018.

Action Contre la Faim (2005) Water, sanitation and hygiene for populations at risk. https://www.ircwash.org/sites/default/files/acfi-2005-water.pdf. Accessed 7 Mar 2019.

Age and Disability Consortium (2018) Humanitarian inclusion standards for older people and people with disabilities. https://reliefweb.int/report/world/humanitarian-inclusion-standards-older-people-and-people-disabilities. Accessed 14 Nov 2018.

Baghri S, Wilson T (2004) Plan's approach to water and environmental sanitation. https://www.plan-international.org. Accessed 10 Mar 2019.

Bangladesh Government (2017) Operational Guidelines for WASH in Emergencies – Bangladesh.https://www.humanitarianresponse.info/sites/www.humanitarianresponse.info/files/documents/files/final_draft_wash_guideline_23feb17.pdf. Accessed 14 Nov 2018.

Banzet J (2003) Towards child-friendly latrines in Viet Nam. Waterfront 18–19.

Bastable A, Lamb J (2012) Innovative designs and approaches in sanitation when responding to challenging and complex humanitarian contexts in urban areas. Waterlines 31. doi:10.3362/1756-3488.2012.007.

Bastable A, Russell L, Gb O (2013) Gap Analysis in Emergency Water, Sanitation and Hygiene Promotion. https://www.alnap.org/system/files/content/resource/files/main/hif-wash-gap-analysis-1-incl-urban_0.pdf. Accessed 8 Mar 2018.

Behnke N, Cronk R, Snel M, et al (2018) Improving environmental conditions for involuntarily displaced populations: water, sanitation, and hygiene in orphanages, prisons, and refugee and IDP settlements. J Water Sanit Hyg Dev 1–7. doi: 10.2166/washdev.2018.019.

Brown J, Cavill S, Cumming O, Jeandron A (2012) Water, sanitation, and hygiene in emergencies: Summary review and recommendations for further research. Waterlines 31:11–29. doi: 10.3362/1756-3488.2012.004.

Child Protection Working Group (2012) Minimum standards for child protection in humanitarian action. https://www.unicef.org/iran/Minimum_standards_for_child_protection_in_humanitarian_action.pdf. Accessed 30 Nov 2018.

Deniel K (2006) Children's sanitation in emergencies. Waterlines 24:28. doi:10.3362/0262-8104.2006.012.

Denis J (2015) Sanitation practices for infants and children in emergencies. Dissertation, Cranfield University.

Eclipse Experience (2019) User-Centred Community Engagement. http://www.eclipse-experience.com/user-centred-community-engagement. Accessed 8 Mar 2019.

Farrington, M (2018) Women's Social Architecture Project: Phase 1 Final Report. Cox's Bazaar, Bangladesh. https://oxfam.app.box.com/s/gmiiqfdn7ntbxeve7fikllywfitnkcjy/file/384891125807. Accessed 11 Dec 2018.

Ferron S, Lloyd A (2014) Emergency WASH for children. https://www.elrha.org/wp-content/uploads/2015/02/2014-10-11-Emergency-WASH-for-Children-Final.pdf. Accessed 1 Nov 2018.

Gensch R, Jennings A, Renggli S, Reymond P (2018) Compendium of Sanitation Technologies in Emergencies .https://www.eawag.ch/fileadmin/Domain1/Abteilungen/sandec/schwerpunkte/sesp/Emergencies/compendium_emergencies.pdf. Accessed 22 Feb 2019.

Gustave YG (2011) Sanitation solutions for a refugee camp: Field trial of sanitation for the vulnerable. Dissertation, 2IE Foundation (International Institute for Water and Environmental Engineering).

Harvey P (2007) Excreta Disposal in Emergencies. https://wedc.ac.uk/publications/. Accessed 7 Mar 2019.

House S (2019) Strengthening the humanity in humanitarian action in the work of the WASH sector in the Rohingya response. https://www.humanitarianlibrary.org/resource/strengthening-humanity-humanitarian-action-work-wash-sector-rohingya-response-gender-gbv Accessed 25 Mar 2019.

IASC (2006) Women, girls, boys and men: different needs - equal opportunities. Gender handbook for humanitarian action. https://www.humanitarianinfo.org/iasc/gender. Accessed 6 Mar 2019.

Jabbar GA (2018) Gender-based violence in relation to water, sanitation and hygiene in the informal tented settlements of the Bekaa Valley, Lebanon. Dissertation, University of Leeds.

Johannessen A (2011) Identifying gaps in emergency sanitation Design of new kits to increase effectiveness in emergencies. https://www.susana.org/lang-en/working-groups/wg08/workshop. Accessed 7 Mar 2019.

Johns Hopkins Bloomberg School of Public Health, International Federation of Red Cross and Red Crescent Societies (2008) The John Hopkins and Red Cross Red

Crescent Public health guide in emergencies. https://reliefweb.int/sites/reliefweb.int/files/resources/Forward.pdf. Accessed 30 Nov 2018.

Jones H, Wilbur J (2014) Compendium of accessible WASH technologies. https://washmatters.wateraid.org/publications/compendium-of-accessible-wash-technologies. Accessed 17 May 2017.

Langford M, Bartram J, Roaf V (2017) The Human Right to Sanitation. In: Langford M, Russell AFS (eds) The Human Right to Water: Theory, Practice and Prospects. Cambridge University Press, Cambridge, pp 345–395.

Mazurana D, Benelli P, Gupta H, Walker P (2011) Sex and Age Matter: Improving Humanitarian Response in Emergencies. https://www.globalprotectioncluster.org/_assets/files/tools_and_guidance/age_gender_diversity/Report_Sex_Age_Matter_2011_EN.pdf. Accessed 4 Mar 2019.

Mazurana D, Benelli P, Walker P (2013) How sex-and age-disaggregated data and gender and generational analyses can improve humanitarian response. Disasters 37:S68–S82. doi: 10.1111/disa.12013.

Noortgate J V D, Maes P (2010) Public Health Engineering in Precarious Situations. http://refbooks.msf.org/msf_docs/en/public_health/public_health_en.pdf. Accessed 18 Nov 2018.

O'Kane C (2013a) Guidelines for Children's Participation in humanitarian programming. https://reliefweb.int/sites/reliefweb.int/files/resources/Children_Participation_Humanitarian_Guidelines.pdf. Accessed 31 Mar 2019.

O'Kane C (2013b) Review of children's participation in humanitarian programming. https://www.alnap.org/system/files/content/resource/files/main/children-participation-humanitarian-review.pdf. Accessed 18 Nov 2018.

Obani P (2017) Inclusiveness in humanitarian action — access to water, sanitation & hygiene in focus. Curr Opin Environ Sustain 24:24–29.

OCHA (2018) Global Humanitarian Overview 2019. https://www.unocha.org/global-humanitarian-overview-2019. Accessed 10 Jan 2019.

OCHA (2020) Global Humanitarian Overview 2021. https://www.unocha.org/global-humanitarian-overview-2021. Accessed 8 Feb 2021.

Oxfam (2012) Working with Children in Humanitarian WASH Programmes. https://policy-practice.oxfam.org.uk/publications/oxfam-minimum-requirements-for-wash-programmes-mr-wash-300134. Accessed 30 Nov 2018.

Oxfam (2013) Oxfam Minimum Requirements for WASH Programmes (MR-WASH). https://policy-practice.oxfam.org.uk/publications/oxfam-minimum-requirements-for-wash-programmes-mr-wash-300134. Accessed 18 Nov 2018.

Oxfam (2018) Sani Tweaks. Best practices in sanitation. www.oxfam.org.uk/sanitweaks. Accessed 31 Mar 2019.

Oxfam International, WEDC (2018) Shining a Light: How lighting in or around sanitation facilities affects the risk of gender-based violence in camps. https://oxfamilibrary.openrepository.com/bitstream/handle/10546/620605/gd-shining-light-sanitation-gender-211218-en.pdf?sequence=1. Accessed 20 Feb 2019.

Pink R (2012) Child rights, right to water and sanitation, and human security. Health Hum Rights 14.

REACH Initiative (2015) Comprehensive Child Focused Assessment. Azraq Refugee Camp. https://www.reachresourcecentre.info/system/files/resource-documents/unicef_reach_comprehensive_child_focused_assessment_azraq_refugee_camp_june_2015.pdf. Accessed 21 Feb 2019.

REACH Initiative (2018) Water, Sanitation and Hygiene Follow-up Assessment Monsoon Season (August-October 2018). https://bit.ly/2ACcRCf. Accessed 10 Jan 2019.

Rouse R, Reed R (2013) Solid waste management in emergencies. https://www.who.int/water_sanitation_health/emergencies/WHO_TN_07_Solid_waste_management_in_emergencies.pdf?ua=1. Accessed 7 Mar 2019.

Sandison P (2017) We're Listening: An evaluation of user-centred community engagement in emergency sanitation. https://oxfamilibrary.openrepository.com/bitstream/handle/10546/620617/gd-listening-community-engagement-emergency-sanitation-050219-en.pdf?sequence=1&isAllowed=y. Accessed 15 Feb 2019.

Save the Children (2013) WASH for Children in Emergencies.https://www.elrha.org/wp-content/uploads/2015/02/Annex-E-Hygiene_Promotion_September_Newsletter_2013.pdf. Accessed 10 Jan 2019.

Sphere Association (2018) The Sphere Handbook: Humanitarian Charter and Minimum Standards. www.practicalactionpublishing.org/sphere. Accessed 14 Nov 2018.

SuSanA (2012) Sustainable sanitation for emergencies and reconstruction situations. www.humanitarianreform.org. Accessed 6 Mar 2019.

Tanner S, O'Connor M (2017) A safe place to shine. Creating opportunities and raising voices of adolescent girls in humanitarian settings. https://www.rescue.org/sites/default/files/document/2248/irccompassglobalreport.pdf. Accessed 14 Mar 2019.

Toms C, Macleod H (2006) World Vision International Children in Emergencies Manual.https://www.rescue.org/sites/default/files/document/2248/irccompassglobalreport.pdf. Accessed 14 Mar 2019.

The Alliance for Child Protection in Humanitarian Action (2019) Minimum Standards for Child Protection in Humanitarian Action, 2019 Edition. https://alliancecpha.org/en/CPMS_home. Accessed 30 Dec 2020.

The Alliance for Child Protection in Humanitarian Action (2019) Table of Indicators: Minimum Standards for Child Protection in Humanitarian Action, 2019 Edition. https://alliancecpha.org/en/CPMS_Table_Indicators. Accessed 10 Feb 2021.

UNHCR (2015) Design Guidelines for Emergency Toilets in Refugee Settings. https://wash.unhcr.org/download/design-guidelines-for-toilets-in-refugee-settings/. Accessed 1 Aug 2019.

UNHCR (2018a) Global Trends. Forced Displacement in 2017. https://www.unhcr.org/5b27be547.pdf. Accessed 10 Jan 2019.

UNHCR (2018b) UNHCR Core WASH Indicators. https://wash.unhcr.org/unhcr-wash-standards-and-indicators-for-refugee-settings/. Accessed 25 Jan 2019.

UNHCR (2018c) UNHCR Population Statistics. https://popstats.unhcr.org/en/demographics. Accessed 28 Nov 2018.

UNHCR (2018d) UNHCR WASH Manual. Practical Guidance for Refugee Settings. http://wash.unhcr.org/unhcr-wash-manual-for-refugee-settings/. Accessed 14 Nov 2018.

UNHCR (2020) UNHCR Population Statistics. https://www.unhcr.org/refugee-statistics/download/?url=E1ZxP4. Accessed 8 Feb 2021.

UNICEF (2005) Emergency Field Handbook. A guide for UNICEF staff. https://www.unicef.org/publications/files/UNICEF_EFH_2005.pdf. Accessed 8 Mar 2019.

UNICEF (2010) Core Commitments for Children in Humanitarian Action. www.unicef.org. Accessed 30 Nov 2018.

UNICEF (2017a) UNICEF Target Product Profile: Accessible Latrine Slab for Emergencies.https://www.unicef.org/supply/files/2017.04.05_Accessible_Latrine_Slab_TPP_v2.2.pdf. Accessed 21 Feb 2019.

UNICEF (2017b) Accessible latrine slab for emergencies: Q&As. https://www.unicef.org/supply/files/2017.05.02_QA_Latrine_Slab.pdf. Accessed 21 Feb 2019.

UNICEF (2017c) Guidance: Including children with disabilities in humanitarian action – WASH.https://training.unicef.org/disability/emergencies/downloads/UNICEF_WASH_English.pdf. Accessed 22 Feb 2019.

UNICEF (2018) Humanitarian Action for Children 2018. www.unicef.org/appeals. Accessed 14 Mar 2019.

United Nations (1990) The United Nations Convention on the Rights of the Child. https://www.unicef.org.uk/what-we-do/un-convention-child-rights/. Accessed 7 Nov 2018.

United Nations (2010a) UNGA Resolution 64/292. The human right to water and sanitation. https://undocs.org/en/A/RES/64/292. Accessed 17 Mar 2019.

United Nations (2010b) HRC Res 15/9. Human rights and access to safe drinking water and sanitation. https://undocs.org/A/HRC/RES/15/9. Accessed 17 Mar 2019.

United Nations (2015) UNGA Resolution 70/169. The human rights to safe drinking water and sanitation. https://undocs.org/en/A/RES/70/169. Accessed 17 Mar 2019.

United Nations (2016) Sustainable Development Goal 6. https://sustainabledevelopment.un.org/sdg6. Accessed 15 Nov 2018.

United Nations Committee on the Rights of the Child (2009) General Comment on A12 Right to Be Heard. http://www.crae.org.uk/publications-resources/uncrc-general-comment-on-right-to-be-heard-(article-12)/. Accessed 31 Mar 2019.

Visser M (2012) External Evaluation WASH Provision in Bahn Refugee Camp in Nimba, Liberia.https://www.alnap.org/system/files/content/resource/files/main/acf-bahn-camp-liberia-wash-evaluation-report.pdf. Accessed 7 Mar 2019.

WHO (2008) Managing WHO Humanitarian Response in the Field. https://www.who.int/hac/techguidance/tools/full_manual.pdf. Accessed 14 Nov 2018.

WHO (2018) Health topics: Sanitation. https://www.who.int/topics/sanitation/en/. Accessed 17 Mar 2019.

Yates T, Allen Vujcic J, Leandre Joseph M, et al (2018) Efficacy and effectiveness of water, sanitation, and hygiene interventions in emergencies in low-and middle-income countries: a systematic review. Waterlines 37. doi: 10.3362/1756-3488.17-00016.

Zakaria F, Muratbegovic A, Brdjanovic D, et al (2017) Evaluation of a smart toilet in an emergency camp. Int J Disaster Risk Reduct 27:512–523. doi: 10.1016/j.ijdrr.2017.11.015.

Zomerplaag J, Moojiman A (2005) Child-Friendly Hygiene and Sanitation Facilities in Schools: Indispensable to effective hygiene education.https://www.ircwash.org/sites/default/files/Zomerplaag-2005-Child.pdf. Accessed 10 Mar 2019.

A6 CHILD-SAN sanitation facilities observation checklist

Name of observer: _____ **Date of observation:** _____

Emergency context: _____

Type of sanitation facility: Household (HH) / Communal (C)

Location: Home (H) / School (S) / Child-friendly space (CFS) / Health facility (HF) / Other (O): _____

Gender: Male (M) / Female (F) / Unisex (U)

Reference: *Emergency context*Type*Location*Gender*Number e.g. Adjumani_HH_H_U_1

Notes:

- In each communal toilet facility observe one female and one male toilet
- Photos must not include people

Area	Observation	Tick if photo taken	Notes
General			
Toilet is in an appropriate location	Yes / No		
Communal toilets are gender segregated	Yes / No		
Total number of communal toilets (i.e. including child-friendly toilets)	Male Female		

	Unisex		
Number of communal child-friendly toilets	Male Female Unisex		
Guidance on how to use the communal toilets provided	Yes / No		
Ease of use of communal toilet guidance for children	Easy / Moderate / Difficult		
Access			
Signage provided to toilets	Yes / No		
Ease of use of signage to toilets for children	Easy / Moderate / Difficult		
Path lighting provided	Yes / No		
Path lighting working	Yes / No		
Path wide enough for two people / a wheelchair	Yes / No		
Paths lined with painted rocks / posts	Yes / No		
Path clear of vegetation / debris	Yes / No		
Path topography ease of navigation for children	Easy / Moderate / Difficult		
Path surface ease to walk on for children	Easy / Moderate / Difficult		
Path surface ease to use for a wheelchair	Easy / Moderate / Difficult		
Access to toilet	Ramp / Steps / None		
Width of ramp	mm		
Raised sides	Yes / No		
Ramp sides painted	Yes / No		

Ramp handrails provided	Yes / No		
Height of ramp handrails	mm		
Ease of use of ramp for children / a wheelchair user	Easy / Moderate / Difficult		
Number of steps			
Step riser height	mm		
Step depth	mm		
Textured step surface in place	Yes / No		
Handrail in place	Yes / No		
Height of handrail from floor	mm		
Ease of use of steps to use by children	Easy / Moderate / Difficult		
Width of toilet entrance	mm		
Toilet walls			
Toilet walls in place	Yes / No		
Toilet walls well-maintained	Yes / Moderate / No		
Toilet walls are decorated	Yes / No		
Can people see inside	Yes / No		
Toilet roof			
Toilet roof in place	Yes / No		
Toilet roof well-maintained	Yes / Moderate / No		
Can people see inside	Yes / No		
Toilet door			

Toilet door in place	Yes / No		
Direction of opening	Outwards / Inwards		
Ease of use of door for children	Easy / Moderate / Difficult		
Can people see inside	Yes / No		
Door handle			
Door handle in place	Yes / No		
Door handle type	D-lever / Doorknob / Other		
Door handle working	Yes / No		
Height from floor	mm		
Ease of use of door handle for children	Easy / Moderate / Difficult		
Door lock			
Door lock in place	Yes / No		
Door lock working	Yes / No		
Height from floor	mm		
Ease of use of door lock for children	Easy / Moderate / Difficult		
Inside			
Big enough for two people / a wheelchair to use	Yes / No		
Lighting in place	Yes / No		
Lighting working	Yes / No		
Bad smell	No / Yes / Disgusting		
Clean	Yes / No		

Insects visible	Yes / No		
Toilet seat in place	Yes / No		
Toilet seat intact	Yes / No		
Height of toilet seat from floor	mm		
Squatting platform in place	mm		
Distance between footrests of squatting platform	mm		
Diameter of drop hole	mm		
Grabrails / handrails in place	Yes / No		
Position of grabrail(s) / handrail(s)	Left of toilet Right of toilet Other		
Orientation of grabrail / handrail(s)	Left vertical / horizontal Right vertical / horizontal Other vertical / horizontal		
Is grabrail / handrail moveable	Left Right Other		
Distance of grabrail(s) / handrail(s) from centre of toilet	Left mm Right mm Other mm		
Height of grabrail(s) / handrail(s) from floor	Left mm Right mm		

	Other mm		
Handwashing tap / water container			
Tap / water container in place	Yes / No		
Tap working	Yes / No		
Tap ease of use for a child	Easy / Moderate / Difficult		
Height from floor	Tap mm Basin mm Container mm		
Soap			
Soap in place	Yes / No		
Soap easily located	Yes / No		
Hygiene promotion			
Hygiene promotion material provided	Yes / No		
Ease of use of hygiene promotion material for children	Easy / Moderate / Difficult		

A7 CHILD-SAN sanitation facilities observation checklist: Results from Cox's Bazaar refugee camps

Ref	Area	Observation
General		
1	Toilet is in an appropriate location	Yes: 54% (13 of 24 checklists) No: 46% (11 of 24 checklists)
2	Communal toilets are gender segregated	Yes: 39% (9 of 23 communal toilets) No: 61% (15 of 23 communal toilets)
3	Total number of communal toilets (i.e. including child-friendly toilets)	Male: 6 (of 23 communal toilets) Female: 5 (of 23 communal toilets) Unisex: 14 (of 23 communal toilets)
4	Number of communal child-friendly toilets	Male: 3 (of 6 communal male toilets) Female: 5 (of 5 communal female toilets) Unisex: 3 (of 14 communal unisex toilets)
5	Guidance on how to use the communal toilets provided	Yes: 0% (0 of 23 communal toilets) No: 100% (23 of 23 communal toilets)
6	Ease of use of communal toilet guidance for children	n/a as per Ref 5
Access		
7	Signage provided to toilets	Yes: 0% (0 of 23 communal toilets) No: 100% (23 of 23 communal toilets)
8	Ease of use of signage to toilets for children	n/a as per Ref 7
9	Path lighting provided	Yes: 0% (0 of 23 communal toilets) No: 100% (23 of 23 communal toilets)
10	Path lighting working	n/a as per Ref 9
11	Path wide enough for two people / a wheelchair	Yes: 30% (7 of 23 communal toilets) No: 70% (16 of 23 communal toilets)
12	Paths lined with painted rocks / posts	Yes: 4% (1 of 23 communal toilets) No: 96% (22 of 23 communal toilets)
13	Path clear of vegetation / debris	Yes: 74% (17 of 23 communal toilets) No: 26% (6 of 23 communal toilets)
14	Path topography ease of navigation for children	Easy: 0% (0 of 23 communal toilets) Moderate: 9% (2 of 23 communal toilets) Difficult: 91% (21 of 23 communal toilets)
15	Path surface ease to walk on for children	Easy: 5% (1 of 22 checklists) Moderate: 27% (6 of 22 checklists)

		Difficult: 68% (15 of 22 checklists)
16	Path surface ease to use for a wheelchair	Easy: 0% (0 of 23 checklists) Moderate: 9% (2 of 23 checklists) Difficult: 91% (21 of 23 checklists)
17	Access to toilet	Ramp: 0% (0 of 24 checklists) Steps: 71% (17 of 24 checklists) None: 29% (7 of 24 checklists)
18	Width of ramp	n/a as per Ref 17
19	Raised sides	n/a as per Ref 17
20	Ramp sides painted	n/a as per Ref 17
21	Ramp handrails provided	n/a as per Ref 17
22	Height of ramp handrails	n/a as per Ref 17
23	Ease of use of ramp for children / a wheelchair user	n/a as per Ref 17
24	Number of steps	Average: 5 (range 1 to 25)
25	Step riser height	Average: 232mm (range 152mm to 320mm)
26	Step depth	Average: 310mm (range 220mm to 483mm)
27	Textured step surface in place	Yes: 76% (13 of 17 toilets accessed by steps) No: 24% (4 of 17 toilets accessed by steps)
28	Handrail in place	Yes: 47% (8 of 17 toilets accessed by steps) No: 53% (9 of 17 toilets accessed by steps)
29	Height of handrail from floor	Average: 1,225mm (range 950mm to 1,575mm)
30	Ease of use of steps to use by children	Easy: 0% (0 of 17 toilets accessed by steps) Moderate: 53% (9 of 17 toilets accessed by steps) Difficult: 47% (8 of 17 toilets accessed by steps)
31	Width of toilet entrance	Average: 777mm (range 460mm to 1,070mm)

Toilet walls		
32	Toilet walls in place	Yes: 83% (20 of 24 checklists) No: 17% (4 of 24 checklists)
33	Toilet walls well-maintained	Yes: 90% (18 of 20 toilets with walls) Moderate: 10% (2 of 20 toilets with walls) No: 0% (0 of 20 toilets with walls)
34	Toilet walls are decorated	Yes: 75% (6 of 8 checklists completed for toilets with walls) No: 25% (2 of 8 checklists completed for toilets with walls)
35	Can people see inside	Yes: 4% (1 of 24 checklists) No: 96% (23 of 24 checklists)
Toilet roof		
36	Toilet roof in place	Yes: 92% (22 of 24 checklists) No: 8% (2 of 24 checklists)
37	Toilet roof well-maintained	Yes: 86% (19 of 22 toilets with a roof) Moderate: 14% (3 of 22 toilets with a roof) No: 0% (0 of 22 toilets with a roof)
38	Can people see inside	Yes: 4% (1 of 24 checklists) No: 96% (23 of 24 checklists)
Toilet door		
39	Toilet door in place	Yes: 86% (19 of 22 checklists) No: 14% (3 of 22 checklists)
40	Direction of opening	Outwards: 50% (11 of 22 toilets with doors) Inwards: 50% (11 of 22 toilets with doors)
41	Ease of use of door for children	Easy: 5% (1 of 22 toilets with doors) Moderate: 36% (8 of 22 toilets with doors) Difficult: 59% (13 of 22 toilets with doors)
42	Can people see inside	Yes: 4% (1 of 24 checklists) No: 96% (23 of 24 checklists)
Door handle		
43	Door handle in place	Yes: 64% (14 of 22 toilets with doors) No: 36% (8 of 22 toilets with doors)

44	Door handle type	D-lever: 64% (9 of 14 toilets with door handles) Doorknob: 0% (0 of 14 toilets with door handles) Other: 36% (5 of 14 toilets with door handles)
45	Door handle working	Yes: 100% (14 of 14 toilets with door handles) No: 0% (0 of 14 toilets with door handles)
46	Height from floor	Average: 1,221mm (range 940mm to 1,480mm)
47	Ease of use of door handle for children	Easy: 0% (0 of 12 checklists completed for doors with handles) Moderate: 25% (3 of 12 checklists completed for doors with handles) Difficult: 75% (9 of 12 checklists completed for doors with handles)
Door lock		
48	Door lock in place	Yes: 48% (11 of 23 checklists) No: 52% (12 of 23 checklists)
49	Door lock working	Yes: 100% (11 of 11 door locks) No: 0% (0 of 11 door locks)
50	Height from floor	Average: 1,133mm (range 890mm to 1,400mm)
51	Ease of use of door lock for children	Yes: 40% (4 of 10 checklists completed for doors with locks) No: 60% (6 of 10 checklists completed for doors with locks)
Inside		
52	Big enough for two people / a wheelchair to use	Yes: 33% (8 of 24 checklists) No: 67% (16 of 24 checklists)
53	Lighting in place	Yes: 4% (1 of 24 checklists) No: 96% (23 of 24 checklists)
54	Lighting working	Yes: 100% (1 of 1 toilets with lighting) No: 0% (0 of 1 toilets with lighting)
55	Bad smell	No: 50% (12 of 24 checklists) Yes: 29% (7 of 24 checklists) Disgusting: 21% (5 of 24 checklists)

56	Clean	Yes: 54% (13 of 24 checklists) No: 46% (11 of 24 checklists)
57	Insects visible	Yes: 8% (2 of 24 checklists) No: 92% (22 of 24 checklists)
58	Toilet seat in place	Yes: 91% (21 of 23 checklists) No: 9% (2 of 23 checklists)
59	Toilet seat intact	Yes: 86% (18 of 21 checklists completed for toilets with seats) No: 14% (3 of 21 checklists completed for toilets with seats)
60	Height of toilet seat from floor	Average 31mm (range 5mm to 71mm)
61	Squatting platform in place	Yes: 92% (22 of 24 checklists) No: 8% (2 of 24 checklists)
62	Distance between footrests of squatting platform	Average 194mm (range 170mm to 254mm)
63	Diameter of drop hole	Average 101mm (range 99mm to 102mm)
64	Grabrails / handrails in place	Yes: 0% (0 of 22 checklists) No: 100% (22 of 22 checklists)
65	Position of grabrail(s) / handrail(s)	n/a as per Ref 64
66	Orientation of grabrail / handrail(s)	n/a as per Ref 64
67	Is grabrail / handrail moveable	n/a as per Ref 64
68	Distance of grabrail(s) / handrail(s) from centre of toilet	n/a as per Ref 64
69	Height of grabrail(s) / handrail(s) from floor	n/a as per Ref 64
Handwashing tap / water container		
70	Tap / water container in place	Yes: 21% (5 of 24 checklists) No: 79% (19 of 24 checklists)
71	Tap working	Yes: 80% (4 of 5 taps) No: 20% (1 of 5 taps)
72	Tap ease of use for a child	Easy: 80% (4 of 5 taps) Moderate: 20% (1 of 5 taps) Difficult: 0% (0 of 5 taps)
73	Height from floor	Tap average 583mm (range 500mm to 699mm) Basin average: 500mm (no range)

		Container average 593mm (range 470mm to 914mm)
Soap		
74	Soap in place	Yes: 13% (3 of 23 checklists) No: 87% (20 of 23 checklists)
75	Soap easily located	Yes: 100% (3 of 3 soaps) No: 0% (0 of 3 soaps)
Hygiene promotion		
76	Hygiene promotion material provided	Yes: 39% (9 of 23 checklists) No: 61% (14 of 23 checklists)
77	Ease of use of hygiene promotion material for children	Easy: 89% (8 of 9 materials) Moderate: 0% (0 of 9 materials) Difficult: 11% (1 of 9 materials)

A8 Revised CHILD-SAN sanitation facilities observation checklist

Name of observer: _____ **Date of observation:** _____

Emergency context: _____

Type of sanitation facility: Household (HH) / Communal (C)

Location: Home (H) / School (S) / Child-friendly space (CFS) / Health facility (HF) / Other (O): _____

Gender: Male (M) / Female (F) / Unisex (U)

Reference: *Emergency context*Type*Location*Gender*Number e.g. Adjumani_HH_H_U_1

Notes:

- In each communal toilet facility observe one female and one male toilet
- Photos must not include people

Ref	Area	Observation	CHILD-SAN guidance	Action required
General (Communal toilets only)				
1	Toilet is in an appropriate location	Yes No	Consider (distance/location) where to safely position gender-neutral and gender-segregated children's toilets that is culturally appropriate for both the child and caregiver	
2	Toilets are gender segregated	Yes No		

3	Total number of toilets	Male: Female: Unisex:	A ratio of 1 toilet per 20 children is recommended	
4	Number of toilets for children-only	Male: Female: Unisex:		
5	Guidance on how to use the toilets is provided	Yes (go to Ref 6) No (go to Ref 7)	Consider if (verbal or visual, using simple communication methods) guidance on how to use the toilet needs to be provided	
6	Ease of use of toilet guidance for children	Easy Moderate Difficult		
Access (Communal toilets only)				
7	Signage provided to toilets	Yes (go to Ref 8) No (go to Ref 9)	Position well-lit signs to show the location of the toilets at both adult and child-height, and use simple communication methods, for example, symbols	
8	Ease of use of signage to toilets for children	Easy Moderate Difficult		
9	Path lighting provided	Yes (go to Ref 10) No (go to Ref 11)		
10	Path lighting working	Yes No		

11	Path wide enough for two people / a wheelchair	Yes No	Paths should be wide enough for two people to comfortably pass, and ideally 1800 mm wide to allow two wheelchair users to pass	
12	Paths lined with painted rocks / posts	Yes No	Line paths with painted rocks and provide painted landmark posts to increase visibility	
13	Path ease of use for children	Easy Moderate Difficult		
14	Path ease of use for a wheelchair	Easy Moderate Difficult		
15	Means of access to toilet	Ramp (go to Ref 16) Steps (go to Ref 22) None (go to Ref 30)	Ramps are the preferred solution for access to at least some of the facilities and where used they should have a minimum width of 1000 mm with raised, painted sides (to avoid falling and to increase visibility) and painted handrails recommended for slopes steeper than 1:20	
16	Width of ramp	mm		
17	Ramp has raised sides	Yes No		
18	Ramp raised sides painted	Yes No		
19	Ramp handrails provided	Yes		

		No		
20	Height of ramp handrails	mm		
21	Ease of use of ramp for children / a wheelchair user	Easy Moderate Difficult		
22	Number of steps		The step riser height (150 to 170 mm) and step depth (280 to 420 mm) should be suitable for a child, the step surface should be textured to prevent slippage, and a painted handrail provided for visible support	
23	Step riser height	mm		
24	Step depth	mm		
25	Textured step surface in place	Yes No		
26	Handrail in place	Yes No		
27	Height of handrail from floor	mm		
28	Ease of use of steps to use by children	Easy Moderate Difficult		
29	Entrance accessible by a wheelchair (minimum width of 800mm, with no thresholds or barriers on the ground)	Yes No	Entrances should have a minimum width of 800mm to allow wheelchair access with no thresholds or barriers on the ground	
Toilet walls				

30	Toilet walls in place	Yes (go to Ref 31) No (go to Ref 34)	Consider how open the toilet should be. Children may prefer an open structure without a door, roof or superstructure	
31	Toilet walls well-maintained	Yes Moderate No		
32	Toilet walls are decorated	Yes No	Brightly decorated walls can encourage use, and decoration with child-friendly hygiene promotion material can increase awareness	
33	Can people see inside	Yes No		
Toilet roof				
34	Toilet roof in place	Yes (go to Ref 35) No (go to Ref 37)	Consider how open the toilet should be. Children may prefer an open structure without a door, roof or superstructure	
35	Toilet roof well-maintained	Yes Moderate No		
36	Can people see inside	Yes No		
Toilet door				

37	Toilet door in place	Yes (go to Ref 38) No (go to Ref 50)	Consider how open the toilet should be. Children may prefer an open structure without a door, roof or superstructure	
38	Direction of opening	Outwards Inwards	Doors should open outwards	
39	Ease of use of door for children	Easy Moderate Difficult	Ensure that doors are robust but not too heavy for children to use	
40	Can people see inside	Yes No		
Door handle				
41	Door handle in place	Yes (go to Ref 42) No (go to Ref 46)		
42	Door handle type	D-lever Doorknob Other	D-lever door handles are preferred rather than doorknobs	
43	Door handle working	Yes No		
44	Height from floor	mm	Door handles should be mounted 800 to 900mm above the floor	
45	Ease of use of door handle for children	Easy Moderate		

		Difficult		
Door lock				
46	Door lock in place	Yes (go to Ref 47) No (go to Ref 50)		
47	Door lock working	Yes No		
48	Height from floor	mm	Locks should be positioned at a height of between 680mm and 800mm	
49	Ease of use of door lock for children	Easy Moderate Difficult		
Inside				
50	Big enough for two people / a wheelchair to use	Yes No	Provide enough space for two people to use the toilet to enable supervision, help and teaching, and that accommodates a wheelchair turning radius (1500mm by 1500mm)	
51	Lighting in place	Yes (go to Ref 52) No (go to Ref 53)		
52	Lighting working	Yes No		

53	Bad smell	Yes No		
54	Clean	Yes No		
55	Insects visible	Yes No		
56	Hooks and/or shelves present	Yes No	Provide doors with locks and walls that ensure privacy; easy access to water; hooks and shelves; and discrete disposal facilities to aid the changing of soiled menstruation and incontinence products and clothing	
57	Discrete disposal facilities present	Yes No		
58	Toilet seat in place	Yes (Go to Ref 59) No (go to Ref 61)		
59	Toilet seat intact	Yes No		
60	Height of toilet seat from floor	mm	Toilet-seats should be low (350 to 450 mm from floor level) or a step provided for children to access the toilet-seat	
61	Squatting platform in place	Yes (Go to Ref 62) No (Go to Ref 63)	Squatting plate dimensions should be suitable for a child	

62	Distance between footrests of squatting platform	mm		
63	Diameter of drop hole	mm	Drop-holes should not be so big that a child could fall-in, or be fearful of falling-in: an indicative diameter is 120 mm	
64	Grabrails / handrails in place	Yes (Go to Ref 65) No (Go to Ref 71)	Provide a handle bar and/or handrails to support squatting. Multiple handrails may be needed (vertical, horizontal, various heights)	
65	Position of grabrail(s) / handrail(s)	Left of toilet Right of toilet Other		
66	Orientation of grabrail / handrail(s)	Left vertical / horizontal Right vertical / horizontal Other vertical / horizontal		
67	Is grabrail / handrail moveable	Left Right Other	If a toilet seat or chair is being used, grab rails should be provided on each side of the toilet. One should be moveable or foldable on one side to allow for transferring	

68	Distance of grabrail(s) / handrail(s) from centre of toilet	Left mm Right mm Other mm	Grab rails on each side of the toilet should be located 300 to 350 mm from the centre of the toilet and between 510mm and 640 mm off the ground	
69	Height of grabrail(s) / handrail(s) from floor	Left mm Right mm Other mm		
Handwashing tap / water container				
70	Tap / water container in place	Yes (Go to Ref 71) No (Go to Ref 74)	Ensure that taps are robust but not too heavy for children to use. Large taps with long levers are easier to operate	
71	Tap working	Yes No		
72	Tap ease of use for a child	Easy Moderate Difficult		
73	Height from floor	Tap mm Basin mm Container mm	Water taps should be positioned within reach of a child or wheelchair user, at a height of between 680 to 800 mm / Washbasins (with unobstructed knee clearance for wheelchair users) should be positioned at height of between 650–700 mm and 200 mm deep	
Soap				

74	Soap in place	Yes (Go to Ref 75) No (Go to Ref 76)	Locate soap for ease of use and where a child with visual or mobility disabilities can easily find/reach it	
75	Soap easily located	Yes No		
Hygiene promotion				
76	Hygiene promotion material provided	Yes (Go to Ref 77) No (End)		
77	Ease of use of hygiene promotion material for children	Easy Moderate Difficult		

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Urinary incontinence in children aged 5 to 12 in an emergency setting: lessons learned in Ethiopia

Claire A. Rosato-Scott, Barbara E. Evans, Abraham Varampath, Ben Fehnert, and Dani J. Barrington

Abstract: *This scoping study aimed to be the first to explore the number of children aged 5 to 12 in an emergency setting (Tukaley village, Ethiopia) wetting themselves, and demand for support to manage self-wetting in the home. A survey asked 524 children about their latrine behaviours; and 312 adult caregivers about the latrine behaviours of the children aged 5 to 12 they care for. Few adult caregivers (1 per cent) indicated that children were self-wetting during the day and/or night, and only one child indicated self-wetting (during the day). Yet the survey revealed demand from adult caregivers for household items typically used to manage involuntary self-wetting. This could suggest self-wetting is occurring, but there is a reluctance to disclose it. Given the impact of self-wetting on the lives of children and their adult caregivers, it would be unethical for it not to be considered when developing emergency programmes across sectors including the water, sanitation, and hygiene sector. With further research and modifications to the survey, it could provide greater clarity on the number of children self-wetting and the scale of demand for support to inform emergency programme design.*

Keywords: incontinence, child, emergency, bedwetting, enuresis, Ethiopia

URINARY INCONTINENCE (UI) IS THE involuntary leakage of urine. Leakage can be continuous or intermittent, and if intermittent can happen at any time, day or night (known as enuresis or bedwetting in children). It is difficult to determine the prevalence of UI in children. Numerous studies have been completed, but comparison is rarely possible due to a lack of homogeneity in study design including definitions, study population, means of sampling and enrolment, and methods of data collection. As global reference points, Buckley and Lapitan's (2010) review of the best available evidence found that the prevalence of daytime UI in children decreases with age, from 3.2–9.0 per cent in 7-year-olds, to 1.1–12.5 per cent in 11 to 13-year-olds (albeit most studies reported a prevalence of between 1.1 per cent and 4.2 per cent); and the 6th International Consultation on Incontinence found

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that most studies reported a prevalence of enuresis of 7.0–10.0 per cent at seven years of age, falling to 1.7–4.8 per cent at 11 to 12 years of age (Abrams et al., 2017). Children that wet themselves can experience incontinence-associated dermatitis (similar to nappy rash), skin infections, pressure sores, urinary tract infections, and dehydration (if fluid restriction is used as a management strategy) (Rosato-Scott et al., 2019). The social and emotional impact on their lives and their carers' lives can be significant, and children that wet themselves may also be at risk of abuse from caregivers in response to the leakage (Can et al., 2004; Sapi et al., 2009).

Many studies have investigated the prevalence, management, treatment, and impacts of UI in children in high-income countries (Chang et al., 2017, for example), but less is known about UI in children living in low- and middle-income countries (LMICs) (studies include Sapi et al., 2009; Fockema et al., 2012) and particularly in emergency contexts. For example, at Save the Children at least, incontinence is not included in emergency health data collection templates and would instead be captured in patient notes, yet anecdotally bedwetting is consistently recorded by Child Protection specialists (being a sign of stress and trauma). It is hypothesized that the prevalence of UI in an emergency context will be higher than global estimates for two reasons. First, because of inaccessible and/or inadequate sanitation facilities, a child who has full control of their bladder wets themselves because they do not want/are not able to use the sanitation facilities available – such as communal toilets in a refugee camp (this is known as social urinary incontinence (SUI) (Ryan, 2018)). The second reason is that the child is experiencing stress and trauma. Jurković et al. (2019) identified refugee status as a risk factor in the occurrence of enuresis in children. This is likely due to the cumulative stresses and traumatic experiences of displacement and forced movement, as stress and anxiety have been found to contribute to the causation of enuresis in some children (Nevéus, 2017; Jurković et al., 2019). Although some studies report a higher prevalence of daytime UI in children under stress, the direction of the causal relationship between psychological problems and daytime UI is unclear (Sureshkumar et al., 2000; Buckley and Lapitan, 2010; Abrams et al., 2017). For families with children that wet themselves, managing the condition in an emergency context – whether an established settlement or a camp – could be particularly challenging as required resources may be lacking, including significantly extra water and soap (estimated at five times as much as a person without incontinence); and time to bathe and wash clothes, bedding, and pads (Sphere Association, 2018). The impacts of the condition may also be far-reaching: embarrassment and shame, or social ostracism (for example, due to smell) could prevent children who wet themselves from participation in programming, education, and social activities (Hafskjold et al., 2016).

Jurković et al. (2019) believe that interest in the connection between enuresis and war stressors is on the rise, originating from Ceri et al.'s (2016) single study group of Yazidi refugee children living in Turkey. Yet a review of the literature did not find a specific study on the prevalence of UI (during the day and/or night) in children aged 5 to 12 (those too old to use small potties, but usually too young to safely and confidently use adult latrines during both the day and night) in

an emergency setting, or how best to manage incontinence in children during an emergency. As emergencies progress, the water, sanitation, and hygiene (WASH) sector must move beyond providing initial rapid relief, to 'ensuring conditions that allow people to live with good health, dignity, comfort and safety' (Sphere Association, 2018: 92). Given the impact of UI on the lives of children and their caregivers, it would be unethical for the WASH sector not to consider UI when developing WASH interventions (and preferably with community participation), particularly after the initial stages of an emergency response. Studies that explore UI in children in an emergency context will therefore raise awareness of the condition and support the inclusion of UI on the WASH sector's agenda.

This study aimed to be the first to explore the number of children aged 5 to 12 in an emergency setting wetting themselves, and demand for support to manage self-wetting in the home. The emergency setting was Tukaley in Ethiopia, an established village that hosts an internally displaced person (IDP) population. The study used a survey to ask 1) children aged 5 to 12 about their latrine behaviours; and 2) adult caregivers about the latrine behaviours of the children aged 5 to 12 they care for, as a means to indicate if there were children self-wetting during the day and/or at night. The survey also asked adult caregivers to indicate preferred support options to manage self-wetting in the home.

Materials and methods

The data collection was conducted by Eclipse Experience (Eclipse) and Save the Children (STC, together the Partners) between September 2019 and January 2020 in a protracted emergency setting, Tukaley in Ethiopia. Tukaley is a small *kebele* (village) with a population of 570 households, located north of Kebridahar town in the Korahey Zone of the Somali Region of Ethiopia. The inhabitants of Tukaley are pastoralist families from various parts of the Somali region, internally displaced since early 2010 due to droughts and large-scale loss of cattle (Bourne and Varampath, 2019). STC constructed the first latrines in Tukaley (four blocks of latrines, each with four cubicles) in 2019, and prior to construction the inhabitants practised open defecation (Bourne and Varampath, 2019). As at September 2019, there were 1,131 children aged 5 to 12 living in Tukaley.

The study used the User-Centred Community Engagement (UCCE) methodology to better understand the latrine behaviours and needs of children aged 5 to 12 in Tukaley (Eclipse Experience, 2019). During an emergency, community engagement – and particularly with vulnerable populations – is often insufficient or of too low a quality to enable WASH activities to be better designed for the various needs of the community. Rapid needs assessments seldom enable the collection of significant and reliable data and although a lack of time is definitely a constraint, there are also few tools to support data collection and analysis during this time, and those that do exist are not always used. UCCE was designed in response to these challenges. The methodology is composed of several components, the first being an Interactive Digital Survey (IDS) to quickly identify respondents' problem areas related to the latrine and handwashing facilities.

Participants in the IDS are either children aged 5 to 12 (child respondents), or adults who care for children aged 5 to 12 (adult caregiver respondents). Once the IDS has been conducted (IDS I), an automatically produced report is reviewed by engineers and priority problems are identified. Co-creation sessions are then held with children and adult caregivers (separately) to explore the problem areas in depth and decide on design changes in a participatory way. The design changes that can be implemented are, and after a period of use a second IDS (IDS 2) is conducted to collect feedback on the altered construction and identify whether there is a need for further alterations (Eclipse Experience, 2019).

By early 2019, the UCCE methodology had been successfully proved as a concept in Bangladesh (December 2017, an early emergency context) and Iraq (February 2018, a protracted emergency context), and a further study was planned in Ethiopia. It was at this stage that the lead author asked the Partners if they would be willing to amend the surveys used in Bangladesh and Iraq to explore the number of children aged 5 to 12 in an emergency setting wetting themselves, and demand for support to manage self-wetting in the home. Of relevance to this paper:

- The question asked in the Bangladesh and Iraq adult caregiver IDS 'where do your children currently defecate most often?' was split into four to ask where children 1) currently urinate most often during the day; 2) urinate most often during the night; 3) defecate most often during the day; and 4) defecate most often during the night; and multiple choice answers were expanded to include the home.
- An additional question was added to the adult caregiver IDS, being 'These are images of three household items: a nappy, a bedpan, and a mattress protector. Please point out any items that would be useful for you and your children'.
- Two additional questions were added to the child IDS, asking 'where do you currently urinate most often during the day?' and 'where do you currently urinate most often during the night?'

The final surveys were translated from English to the local language of the IDPs (Somali) by a member of the STC field team based in Ethiopia. IDS I was conducted in September 2019 by five data collectors who were trained by members of Eclipse. The selection criteria for being asked to take part in IDS I were 1) for adults, to reside in a household with children aged between 5 and 12 years old; and 2) for children, to be aged between 5 and 12 years old. Each data collector was assigned an area of the village and over the course of four days, they called at each household once. The number of surveys completed was limited by the time available, and 524 children and 312 caregivers took part (as some caregivers had multiple children within this age bracket).

This paper has only considered data related to three questions asked in the adult caregiver IDS, and two questions asked in the child IDS:

- Adult caregiver respondents answered the questions 'where do your children currently urinate most often during the day?' and 'where do your children currently urinate most often during the night?' by tapping once on the appropriate answer

text: at home in a bed, at home in a bucket, outside of home around the camp, camp latrines, child-friendly spaces latrines, or other. If other was given as an answer, the data collector asked for more detail and input text to the IDS.
- Adult caregiver respondents also answered the question 'These are images of three household items: a nappy, a bedpan, and a mattress protector. Please point out any items that would be useful for you and your children' by tapping on the relevant image(s).
- Child respondents aged 5 to 12 answered the questions 'where do you currently urinate most often during the day?' and 'where do you currently urinate most often during the night?' by tapping once on an illustration with images depicting home, outside of home around the camp, camp latrines or bush. If home was given as an answer, the data collector asked the respondent 'Where at home?', and the respondent answered by tapping once on an illustration with images depicting a child (representing the respondent), a bed, and a bucket.

The anonymous data was stored on a server managed by AidIQ under a subcontract from Eclipse. The lead author viewed the aggregated data on an online hub using a username and password, and the raw data (with individual responses identified by time stamp of survey completion) was also exported in a Microsoft Excel format for analysis. Descriptive statistics were computed to assess the distribution of answers given by adult caregiver respondents and child respondents to 1) where do your children/you currently urinate most often during the day and 2) where do your children/you currently urinate most often during the night; and to assess the distribution of answers given by adult caregiver respondents to the question on household item choices as a means to triangulate the data.

Ethical considerations

The amendments made to the survey for the purpose of exploring the number of children wetting themselves, and demand for support to manage self-wetting in the home were designed to ensure that:

- the primary purpose of the survey (to quickly identify, with minimum intrusion for participants, the most common problem areas children experience during their latrine journey) was not altered;
- there was no mention or suggestion of UI to ensure that such experiences were not interpreted by the survey participants as being problematic, particularly given that support to manage the condition was not being immediately offered.

At each household visited, the data collectors asked the adult residents if there were any children within the target age group (5 to 12 years old) living in the home. If there were any children within the target age group living in the household, the data collector verbally provided information about IDS I (including its purpose and the type of questions that would be asked) to the adult resident, and then asked the adult resident if they would 1) verbally consent to taking part in IDS I, and 2) verbally consent for the children in the household aged between 5 and 12 years old to being asked to assent to take part in IDS I. If the adult resident gave

consent to ask the child(ren) aged 5 to 12 in the household to take part in IDS I, the data collector verbally provided child-appropriate information about IDS I to the child(ren) aged 5 to 12 and then asked them individually if they would verbally assent to taking part. Only after verbal consent/assent was obtained was the IDS conducted.

Approval to conduct the Ethiopia study was granted by the STC Deputy Country Director in Ethiopia. The lead author's use of data from the Ethiopia study was approved by the Research Ethics Committee, Faculty of Engineering, University of Leeds, United Kingdom (Reference MEEC 19-018).

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Results

Of the 312 adult caregivers, 223 (71 per cent) reported that their children aged 5 to 12 urinate most often during the day at the camp latrines and 398 (76 per cent) of children aged 5 to 12 reported the same (Table 1). Four caregivers reported that their children aged 5 to 12 urinate most often during the day at home in bed, and two reported urination most often during the day at home in a bucket. Only one child self-reported urinating most often during the day at home, which was in bed.

Table 1 The location of daytime urination of children aged 5 to 12 in Tukaley, Ethiopia

Location[1]	*Interactive Digital Survey I respondent group*			
	Adult caregivers (responding on behalf of children cared for aged 5–12)		*Children aged 5–12 (self-reporting)*	
	(n)	*(%)*	*(n)*	*(%)*
Camp latrines	223	71	398	76
Outside of home, around the camp	67	21	44	8
Bush	Not an answer option[1]		79	15
Child-friendly spaces latrines	12	4	Not an answer option[1]	
At home, in bed	4	1	Not an answer option[1]	
At home, in a bucket	2	1	Not an answer option[1]	
At home	Not an answer option[1]		1	0
Other	4	1	Not an answer option[1]	
Total	**312**	**100**	**522**[2]	**100**

[1] Survey respondents were given different answer options dependent on their respondent group: 1) adult caregivers or 2) children aged 5 to 12.
[2] Two respondents did not answer.

Table 2 The location of nighttime urination of children aged 5 to 12 in Tukaley, Ethiopia

Location[1]	*Interactive Digital Survey I respondent group*			
	Adult caregivers (responding on behalf of children cared for aged 5–12)		*Children aged 5–12 (self-reporting)*	
	(n)	*(%)*	*(n)*	*(%)*
Camp latrines	204	65	298	57
Outside of home, around the camp	99	32	182	35
Bush	Not an answer option[1]		41	8
Child-friendly space latrines	1	0	Not an answer option[1]	
At home, in bed	3	1	Not an answer option[1]	
At home, in a bucket	1	0	Not an answer option[1]	
At home	Not an answer option[1]		0	0
Other	4	1	Not an answer option[1]	
Total	**312**	**100**	**521**[2]	**100**

[1] Survey respondents were given different answer options dependent on their respondent group: 1) adult caregivers or 2) children aged 5 to 12.
[2] Three respondents did not answer.

Of the 312 adult caregivers, 204 (65 per cent) reported that their children aged 5 to 12 urinate most often during the night at the camp latrines, and 298 (57 per cent) of children aged 5 to 12 reported the same (Table 2). Of the caregivers, 99 (32 per cent) reported that their children aged 5 to 12 urinate most often during the night outside of home around the camp, and 223 (43 per cent) children aged 5 to 12 also reported urinating most often during the night outside of the home (including in a bush). Three caregivers reported that their children aged 5 to 12 urinate most often during the night at home in bed, and one reported urination most often during the night at home in a bucket. No child self-reported frequent urination at home during the night.

Of the 312 adult caregivers, 289 (93 per cent) indicated that a bedpan would be useful for them and their children; 73 (23 per cent) selected a nappy; and 59 (19 per cent) chose a mattress protector (Table 3).

Table 3 Household items selected by adult caregivers that would be useful for them and their children

Household item[1]	*Adult caregivers*	
	(n)	*(% of 312 respondents)*
Bedpan	289	93
Nappy	73	23
Mattress protector	59	19

[1] Survey respondents could select up to three answers.

Discussion

Of the adult caregivers, 1 per cent (4 of 312) reported that their children aged 5 to 12 urinate most often during the day at home in bed. The number of children to which this relates is unknown: on average adult caregivers reported that three children aged 5 to 12 lived in their household and they may have answered the question thinking about one child in particular, or the children as a group. The age and gender of the children to which these answers relate are therefore also unknown. Only one child of the 522 that completed the IDS self-reported urinating most often during the day at home, which was in bed. The age and gender of the child is unknown as the answer was provided by tapping the screen, and the IDS currently lacks the functionality to report the location of the tap by individual data record (identified by time stamp). Children wetting the bed during the day could have daytime UI, but the results suggest a much lower number of children than global prevalence data indicates: Buckley and Lapitan (2010) found that the prevalence of daytime UI in children decreases with age, from 3.2–9.0 per cent in 7-year-olds, to 1.1–12.5 per cent in 11 to 13-year-olds, albeit most studies reported a prevalence of between 1.1 per cent and 4.2 per cent.

Of the adult caregivers, 1 per cent (3 of 312) reported that their children aged 5 to 12 urinate most often during the night at home in bed, but no child self-reported frequent urination at home during the night. Children wetting the bed at night could have enuresis, but for the same reasons as cited above, prevalence data by age cannot be calculated for this study. Again the results suggest a much lower number of children that could potentially have enuresis than global estimates: the 6th International Consultation on Incontinence found that most studies reported a prevalence of enuresis of 7.0–10.0 per cent at 7 years of age, falling to 1.7–4.8 per cent at 11 to 12 years (Abrams et al., 2017).

Understanding of UI in LMICs, and including emergency settings, is still in its early stages. Previous research conducted in Zambia found a low level of disclosure by adults that they were experiencing incontinence symptoms (that is, self-wetting), with a reluctance to disclose attributed to a lack of awareness that incontinence is a medical condition, and/or the stigma associated with the condition (Rosato-Scott and Barrington, 2018). Interviews with adults and their caregivers revealed this reluctance to disclose rather than an absence of UI, and this is supported by systematic reviews looking at the prevalence of adults experiencing UI in LMICs which find rates in line with global estimates (Walker and Gunasekera, 2011; Rosato-Scott and Barrington, 2018; Mostafaei et al., 2020).

This study assumed that the number of children self-wetting in Tukaley would also be in line with global estimates, or even higher due to the impact of stress and trauma, but this may not hold true. Ashenafi et al. (2001) conducted a survey of mental and behavioural disorders in children aged 5 to 15 years in rural Butajira, a district of southern Ethiopia. The study diagnosed enuresis in 0.8 per cent of the study children (that is, across the age range) through interviews with their caregivers (Ashenafi et al., 2001). Ashenafi et al. (2001) were surprised by their results and concluded that caregivers may not be reporting the condition in children as they do not recognize it (due to, for example, children in rural areas sleeping alone and

parents rarely changing children's clothes or making their beds) and children may not be reporting the condition to parents due to the stigma associated with it. Desta et al. (2007) further hypothesized that in rural areas caregivers may not detect bedwetting due to a lack of bedding (commonly children sleep on hay) and the smell of animal excreta masking the smell of human urine (where animals and humans spend the night in the same room).

The prevalence of UI could also be low in Tukaley relative to global estimates. However, when given the choice many adult caregivers selected household items (and some selected multiple household items) that are typically used to manage urinary leakage (bedpans, nappies, and mattress protectors). The selection of nappies (23 per cent, or 73 of 312 caregivers) and mattress protectors (19 per cent, or 59 of 312 caregivers) is indicative of having to manage a problem of involuntary self-wetting. The results of the IDS could therefore indicate a lack of caregiver knowledge about the latrine behaviours of the children they care for and/or a reluctance to disclose. Caregivers may not know where the children they care for usually urinate during the day and night: prior to the installation of latrines in the village open-urination was practised. There may also be a reluctance to report children wetting the bed/self-wetting due to the stigma associated with doing so. Yet 93 per cent (289 of 312) of adult caregivers also selected bedpans. This suggests that a child would voluntarily be able to use it; that is, they are not wetting themselves without control (either during the day or during sleep). This could indicate a reluctance to leave the home to urinate (SUI) rather than having the medical condition of UI. Further, the selection of answers may not actually be related to managing children self-wetting at all: items could have been selected to be used by an adult to manage self-leakage or for completely other purposes, for example to collect rainwater (mattress protector) or store water (bedpan). Without interviews with caregivers and children to interrogate the IDS data, such hypotheses cannot be further explored and it is not possible to determine if the result can be generalized to rural populations of IDPs located elsewhere in Ethiopia and further afield.

Limitations

This was a scoping study to explore the number of children aged 5 to 12 in an emergency setting wetting themselves, and demand for support to manage self-wetting in the home, using a survey-based methodology. However, in the absence of interviews with participants it is not possible to interrogate the data to fully understand the true meaning of the answers given. Further, the study was limited to participants who were available at the time of the household visit, and each household was only visited once. This may affect the generalizability of the findings.

Conclusions

Four of 312 caregivers reported that their children aged 5 to 12 urinate most often during the day at home in bed (number of children, age, and gender unknown); one child (of 522 that answered the IDS, age and gender unknown) self-reported

urinating most often during the day at home in bed; 3 of 312 caregivers reported that their children aged 5 to 12 urinate most often during the night at home in bed (number of children, age, and gender unknown); and not one child (of the 521 that answered the IDS) self-reported urinating most often during the night at home in bed. If it is suggested that children wetting the bed during the day and/or night could have UI, this is an unexpected result relative to global estimates (Buckley and Lapitan, 2010; Abrams et al., 2017).

The number of children self-wetting could be relatively low in Tukaley, but IDS answers indicating demand for nappies and mattress protectors suggests a greater need for support to manage self-wetting than would be expected given the low number of children self-wetting. The results may therefore indicate a reluctance to disclose (by both adult caregivers and children) due to the stigma associated with incontinence, and the study has identified a further context in which incontinence is a taboo subject. However, a high demand for bedpans was also revealed, which suggests a reluctance to leave the home to urinate (SUI) rather than involuntary leakage (UI). Further, demand for bedpans, nappies, and mattress protectors could be indicative of different problems to be managed, for example, adult self-wetting and/or the need to store water. Without interviews with caregivers and children to interrogate the IDS data such hypotheses cannot be further explored.

Little is known about how displaced children understand and experience health. Migrant research to date has tended to prioritize adult frames of reference, including caregiver's perspectives on children's health-related experiences and needs even though adults do not necessarily make good proxies for children (Curtis et al., 2018; Spencer et al., 2019). The IDS is distinctive in that children themselves participate, and the Ethiopia study was therefore an ideal opportunity to explore the latrine behaviours of the children in greater detail. Amending the questions asked provided deeper insight into how and why the children were using (or not using) the latrines in Tukaley; additional changes could provide further understanding about the number of children wetting themselves in an emergency context and the need for support to manage self-wetting without unnecessarily burdening the data collectors (remember that the primary purpose of the IDS is to quickly identify, with minimum intrusion for participants, the most common problem areas children experience during their latrine journey). For example, adult caregiver answer options could be amended to more clearly identify self-wetting. Current answer options are at home in a bed, at home in a bucket, outside of home around the camp, camp latrines, child-friendly spaces latrines, or other. The authors suggest that adult caregiver answer options are revised to at home (which if selected triggers further answer options depicted using images of a child, a bed, and a bucket), outside of home around the camp, camp latrines, child-friendly spaces latrines, or other. Ideally, these answers would be aligned with the children's answer options to allow a quick and easy comparison. It is also suggested that interviews are held with participants (retrospectively or with participants of future studies) to explore how the question on identifying the need for household items is interpreted by respondents – and if anything else should be added, for example, additional soap – in order to amend it as necessary to more clearly identify demand for support to manage self-wetting (and perhaps for adults as well as children). It is noted that this

survey was not designed to determine the prevalence of UI in children and further research is therefore needed to calculate the prevalence of UI in children aged 5 to 12 in an emergency context. Ideally such a study would also incorporate comparable research in a non-emergency context to determine if prevalence rates are impacted by the stress and trauma associated with emergencies.

Such amendments to the UCCE methodology would be of great use to multiple sectors (including health, protection, children, and WASH) as a means to quickly provide an indication of the numbers of children self-wetting and identify if self-wetting is an issue that requires programmatic support. However, this is reliant on adult caregiver IDS participants being willing to report that the children they care for wet themselves and/or the bed, and child IDS participants self-reporting self-wetting. Where incontinence is a taboo subject, this study suggests that disclosure levels may be low even if support is wanted. The experience of self-wetting can have negative implications for the life of a child medically, socially, and emotionally, and increase the risk of abuse. Support should therefore be provided to manage self-wetting where possible. Research conducted to determine if and how much UI exists in an emergency context may increase awareness across sectors that it should be included on their emergency response agendas, but it should not be necessary to justify providing support for its symptoms where demand is clearly indicated. The IDS is therefore recommended as a tool to focus on the scale of the support needed, rather than to deeply explore why such support is requested.

Final thoughts for the WASH sector

- Families with children that wet themselves will require additional water, soap, and time to bathe and wash clothes, bedding, and pads.
- Camp latrines may never be suitable for all children aged 5 to 12 to use at night (due to, for example, a fear of the dark) and some children may prefer to urinate (and defecate) outside close to home which could be unsafe and unhygienic. The distribution of items to support hygienic urination (and defecation) in the home would discourage open urination (and defecation).
- Surveys to determine the need for household items may not reveal the underlying reason for selection. For example, in this instance it is not known if there is a high demand for bedpans to urinate in, or for an alternative purpose such as to store water. Interviews are therefore recommended to supplement surveys to ensure that the most appropriate household items are distributed.

References

Abrams, P., Cardozo, L., Wagg, A. and Wein, A. (eds) (2017) *Incontinence*, 6th edition [online], Bristol: International Continence Society <https://www.ics.org/education/icspublications/icibooks/6thicibook> [accessed 21 November 2018].

Ashenafi, Y., Kebede, D., Desta, M. and Alem, A. (2001) 'Prevalence of mental and behavioural disorders in Ethiopian children', *East African Medical Journal* 78: 308–11 <http://dx.doi.org/10.4314/eamj.v78i6.9024>.

Bourne, S. and Varampath, A. (2019) 'Giving children and caregivers a stronger voice in emergency WASH response' [blog], Reliefweb <https://reliefweb.int/report/ethiopia/giving-children-and-caregivers-stronger-voice-emergency-wash-response> [accessed 14 March 2020].

Buckley, B.S. and Lapitan, M.C.M (2010) 'Prevalence of urinary incontinence in men, women, and children – current evidence: findings of the Fourth International Consultation on Incontinence', *Urology* 76: 265–70 <https://doi.org/10.1016/j.urology.2009.11.078>.

Can, G., Topbas, M., Okten, A. and Kizil, M. (2004) 'Child abuse as a result of enuresis', *Paediatrics International* 46: 64–6 <https://doi.org/10.1111/j.1442-200X.2004.01829.x>.

Ceri, V., Özlü-Erkilic, Z., Özer, Ü., Yalcin, M., Popow, C. and Akkaya-Kalayci, T. (2016) 'Psychiatric symptoms and disorders among Yazidi children and adolescents immediately after forced migration following ISIS attacks', *Neuropsychiatrie* 30: 145–50 <https://doi.org/10.1007/s40211-016-0195-9>.

Chang, S.J., Van Laecke, E., Bauer, S.B., Von Gontard, A., Bagli, D., Bower, W.F., Renson, C., Kawauchi, A. and Shei-Dei Yang, S. (2017) 'Treatment of daytime urinary incontinence: a standardisation document from the International Children's Continence Society', *Neurology and Urodynamics* 36: 43–50 <https://doi.org/10.1002/nau.22911>.

Curtis, P., Thompson, J. and Fairbrother, H. (2018) 'Migrant children within Europe: a systematic review of children's perspectives on their health experiences', *Public Health* 158: 71–85 <https://doi.org/10.1016/j.puhe.2018.01.038>.

Desta, M., Hägglöf, B., Kebede, D. and Alem, A. (2007) 'Socio-demographic and psychopathologic correlates of enuresis in urban Ethiopian children', *Acta Paediatrica* 96: 556–60 <https://doi.org/10.1111/j.1651-2227.2007.00229.x>.

Eclipse Experience (2019) 'User-Centred Community Engagement' [website] <http://www.eclipse-experience.com/user-centred-community-engagement> [accessed 8 March 2019].

Fockema, M.W., Candy, G.P., Kruger, D. and Haffejee, M. (2012) 'Enuresis in South African children: prevalence, associated factors and parental perception of treatment', *BJU International* 110: 1114–20 <https://doi.org/10.1111/j.1464-410X.2012.11416.x>.

Hafskjold, B., Pop-Stefanija, B., Giles-Hansen, C., Weerts, E., Flynn, E., Wilbur, J., Brogan, K., Ackom, K., Farrington, M., Peuschel, M., Klaesener-Metzner, N., Cordero, R., Cavill, S. and House, S. (2016) 'Taking Stock: Incompetent at incontinence – why are we ignoring the needs of incontinence sufferers?' *Waterlines* 35(3) <http://dx.doi.org/10.3362/1756-3488.2016.018>.

Jurković, M., Tomašković, I., Tomašković, M., Zore, B.S., Pavić, I. and Roić, A.C. (2019) 'Refugee status as a possible risk factor for childhood enuresis', *International Journal of Environmental Research and Public Health* 16(7): 1293 <http://dx.doi.org/10.3390/ijerph16071293>.

Mostafaei, H., Sadeghi-Bazargani, H., Hajebrahimi, S., Salehi-Pourmehr, H., Ghojazadeh, M., Onur, R., Al Mousa, R.T. and Oelke, M. (2020) 'Prevalence of urinary incontinence in the developing world: a systematic review and meta-analysis – a report from the Developing World Committee of the International Continence Society and Iranian Research Center for Evidence Based Medicine', *Neurourology and Urodynamics* 39(4): 1063–86 <http://dx.doi.org/10.1002/nau.24342>.

Nevéus, T. (2017) 'Pathogenesis of enuresis: towards a new understanding', *International Journal of Urology* 24: 174–82 <http://dx.doi.org/10.1111/iju.13310>.

Rosato-Scott, C.A. and Barrington, D.J. (2018) 'Incontinence in Zambia: initial investigation into the coping strategies of sufferers and carers', *Waterlines* 37: 190–206 <http://dx.doi.org/10.3362/1756-3488.18-00012>.

Rosato-Scott, C.A., Giles-Hansen, C., House, S., Wilbur, J., Macauley, M., Barrington, D., Culmer, P. and Burke, L. (2019) *Guidance on Supporting People with Incontinence in Humanitarian and Low- and Middle-Income Contexts (LMICs)* [online], University of Leeds <http://dx.doi.org/10.5518/100/13>.

Ryan, F. (2018) '"It's horrifically painful": the disabled women forced into unnecessary surgery', *The Guardian*, 6 August 2018 [online] <https://www.theguardian.com/society/2018/aug/06/disabled-women-surgery-catheter-accessible-toilets> [accessed 27 February 2019].

Sapi, M.C., Vasconcelos, J.S.P., Silva, F.G., Damião, R. and Da Silva, E.A. (2009) 'Assessment of domestic violence against children and adolescents with enuresis', *Jornal de Pediatria* 85: 433–7 <http://dx.doi.org/10.2223/JPED.1935>.

Spencer, G., Smith, M., Thompson, J., Fairbrother, H., Hoare, K., Fouché, C. and Curtis, P. (2019) 'Health experiences of children and young people who migrate: opportunities for health education', *Health Education Journal* 78: 96–107 <http://dx.doi.org/10.1177/0017896918786767>.

Sphere Association (2018) *The Sphere Handbook: Humanitarian Charter and Minimum Standards in Humanitarian Response*, 4th edition [online], Geneva, Switzerland: Sphere Association <https://practicalactionpublishing.com/book/2048/the-sphere-handbook> [accessed 21 May 2021].

Sureshkumar, P., Craig, J.C., Roy, L.P. and Knight, J.F. (2000) 'Daytime urinary incontinence in primary school children: a population-based survey', *The Journal of Pediatrics* 137: 814–8 <http://dx.doi.org/10.1067/mpd.2000.109196>.

Walker, G.J.A. and Gunasekera, P. (2011) 'Pelvic organ prolapse and incontinence in developing countries: review of prevalence and risk factors', *International Urogynecological Journal* 22: 127–35 <http://dx.doi.org/10.1007/s00192-010-1215-0>.

A10 Manuscript 4 S1 Supporting Information: Extracts from the PhD thesis of C. Rosato-Scott detailing development of the Story Book Methodology

Using a rights-based approach, the starting-point from which to decide whether children should participate in any research project is that children have a right to be heard, even in a situation of crisis or its aftermath (1,2). From an initial stance of 'involving children in research is the right thing to do', researchers must decide if – for their particular project – it shouldn't be done because a) the matter being researched doesn't concern the child participants directly or indirectly; b) the researchers lack the capacity to either conduct the research or act on the findings; and/or c) the research could not be conducted ethically. When planning the research activities to be undertaken in Adjumani District and Cox's Bazar, the Research Team considered these questions in turn:

a) Is the research of relevance to the children?

The Research Team concluded that the subject matter of the research (that is, the experiences of children living with incontinence) was directly of concern to the proposed child participants, and that only they – and not an adult proxy – could genuinely voice their experiences.

b) Does the Research Team have the capacity to conduct the research and act on the findings?

Of primary concern when involving children in research is to ensure that all necessary steps will be taken to safeguard the participants (3).This requires having researchers in the team with the minimum knowledge, skills and attitudes needed to facilitate and support meaningful participation with children (4 p.21). There is no shared standard for assessing a researcher's competencies and capacities; instead assessment is subjective and context-specific (5). Guidelines such as (4 p.21) that provide ideal researcher specifications are therefore invaluable when recruiting those that will conduct the research. In Bangladesh the focus group facilitators were hygiene officers used to working with children. In Uganda the facilitators were research assistants from the Plan International Uganda database, known to have experience in qualitative data collection and who were familiar with the local community. The skills and experiences of the data collectors therefore met O'Kane's minimum requirements including knowledge of local context; facilitation skills; and having an attitude that valued children (4 p.21). The participation of Plan International UK, Plan International Uganda, UNICEF Bangladesh and World Vision Bangladesh was viewed as a demonstration of an organisational

mandate to a) learn more about how to best support people living with incontinence in a humanitarian context, and b) to incorporate the findings into their existing WASH programmes.

c) Can the research be conducted ethically?

As effective methodology and ethics go hand in hand, determining how the children would participate was crucial to deciding if the research could be conducted ethically (6). In late-2019, UK-based members of the Research Team met to initially design the research tools to be used. Virtual workshops (rather than in-person due to Covid-19) were then held in July 2020 with Australia-, Uganda- and UK-based members of the Research Team to contextualise the research methodology and individual tools to be used in Adjumani District; and in December 2020, with Australia- and Bangladesh-based members of the Research Team to contextualise the research methodology and individual tools to be used in Cox's Bazar.

The research methodology was developed with the competencies and capacities of the proposed data collectors in mind. The day-to-day work of the proposed data collectors included focus group discussions (FGDs) and interviews with children aged five to 11, therefore the first decision point was whether to conduct FGDs or interviews. The Research Team's preference was to avoid conducting interviews with young children to avoid any repercussions should a participant be viewed as having been specifically selected to take part in a conversation about such a highly personal, sensitive and often stigmatised medical condition (UI). It was also felt that an interview on such a topic could be an intimidating process for a young child with little benefit for them.

In contrast, FGDs are "purposeful, facilitated discussions between a group of participants with similar characteristics" (7 p.5). They generate data through interaction amongst the participants; and compared to an interview responses are deeper and more considered as participants have the opportunity to listen to others, reflect and consider their own viewpoint, and there is more scope for the natural emergence of issues (8). This is of course all reliant on the culture of the participants encouraging free expression and the Bangladesh- and Uganda-based members of the Research Team provided assurance that children in Cox's Bazar and Adjumani District were able to express themselves in the context of a FGD without fear of punishment (5).

Agar et al. (3) found that FGDs work well with children, and they have also been shown to be an ideal qualitative research method when discussing sensitive topics with children:

the group context can provide mutual support for shy children, articulate children can model for those lacking in confidence, and the peer support helps to redress the power imbalance that exists between adult and child during an interview (7,9). However, researchers need to balance the benefits of FGDs with the risks that a) disclosures may be shared outside of the group, and b) that discussion may stress or distress participants (3). Verbal introductions to FGDs must therefore outline that although the children can discuss the FGD with non-participants, details including who said what should not be shared, however there is a risk that they may be (3). The FGD facilitator must also emphasise that participation is voluntary, and anyone can leave at any time for any reason including if they do not want to speak or hear what is being said. Having a second person present to observe can also support the facilitator to recognise signs of stress or distress in participants, and take the appropriate action (10). The Research Team therefore concluded that conducting FGDs would be appropriate.

The size and composition of a focus group is critical in shaping the group dynamic (8). Members of the Advisory Team guided that FGDs with children should have up to six participants, which is in-line with the literature: (8) found that children are likely to feel more comfortable in a smaller group. Given the personal and sensitive nature of the issues being discussed, it was felt that groups should be split by gender, and it was also decided that groups should be split by age. This was partly due to the knowledge that the global prevalence of UI follows a trend of decline by age and therefore different age groups may have different experiences of the condition; but also following guidance from the Bangladesh Research Team who felt that children aged eight or more were noticeably more mature. The split was decided as five to seven-years old and eight to 11 years old. Further, the Bangladesh Research Team advised that the facilitator of the FGD should be of the same gender as the participants, particularly for the older ages (eight to 11) as otherwise they may be too embarrassed to contribute.

The research methods used during FGDs should reflect the capacities of the participants and ideally provide an opportunity for recreation and self-expression, particularly in a humanitarian context where such opportunities could be rare and therefore even more valuable (11). The use of drawing methods in research with children is known to be very successful as they can minimise the power relationship between adult researchers and the children; give participants time to think about what they want to communicate; help discussions about more complicated, sensitive and abstract issues; uncover subconscious perspectives; provide learning opportunities; and be fun and relaxing (6,12,13). Indeed in Cox’s Bazar members of the Bangladesh Research Team were already adapting methods used by Clowns Without Borders to educate the children on

topics such as hand-washing. These methods included singing songs, playing games, telling stories, and drawing pictures.

The Research Team therefore designed a collaborative 'Story Book methodology', whereby the children collectively drew on sheets ('Drawing Sheets' with outline images provided) to create a story about an imaginary child living in Adjumani District or Cox's Bazar who sometimes wet themselves. The group explored the feelings of the imaginary child at different times during the day (for example, when playing with friends) and including when they wet themselves, and the feelings of the imaginary child's caregiver after an episode of self-wetting. The group also explored a time period, for example a morning, in the life of the imaginary child to understand the wider impacts of an episode of self-wetting and to ask the children for suggestions as to how to mitigate such impacts. Note that the use of an imaginary child rather than asking participants to share personal experiences of incontinence reduced the risk of a) a child becoming distressed at being asked to share such experiences and b) a participant being identified by friends, family and the wider community as experiencing incontinence which may result in negative consequences due to the stigma associated with the condition. This 'imaginary' approach was particularly favoured by the Bangladesh Research Team as some members knew of children that had participated in FGDs on menstrual hygiene management and who were later teased by fellow participants.

Given the age of the participants the Research Team agreed that the provision of compensation should be limited to the food and drinks provided during the FGD. And finally, (14) advise that methods and tools used in FGDs should be "informed by discussions with the children themselves and with adult community members" (p.20), and so the tools were modified after each FGD, informed by the children themselves. For example, after the first pilot FGD additional breaks were added to the FGD to ensure that the attention of the children was kept.

References

1. United Nations. The United Nations Convention on the Rights of the Child [Internet]. New York, United States; 1990. Available from: https://www.unicef.org.uk/what-we-do/un-convention-child-rights/
2. United Nations Committee on the Rights of the Child. General Comment No.12. on the Right of the Child to be Heard [Internet]. Geneva, Switzerland; 2009. Available from: https://www.refworld.org/docid/4ae562c52.html
3. Agar, M., Macdonald, J., Basch, C.E., Bertrand, J.T., Brown, J.E., Ward, V.M., Bogardus, E.S., Charlesworth, L.W., Rodwell, M.K., Clark, C.D., Clark, L., Marsh,

G.W., Davis, M., Igoe, J., Stember, M., Doswell, W.M., Vandestienne, G., Elliott, R., Fischer, C.T., Rennie, D.L., Garley, D., Gallop, R., Johnston, N., Pipitone, J., Greenbaum, T.L., Heary, C., Hennessy, E., Hill, M., Laybourn, A., Borland, M., Houghton, S., Durkin, K., Carroll, A., Hunter, A.J., Chandler, G.E., Kidd, P., Townley, K., Cole, H., Mcknight, R., Piercy, L., Kisker, E.E., Klein, J.D., Forehand, B., Oliveri, J., Patterson, C.J., Kupersmidt, J.B., Strecher, V., Krueger, R.A., Levine, I.S., Zimmerman, J.D., Lewis, A., Maccoby, E.E., Macmullin, C., Odeh, J., Mauthner, M., Mayall, B., Mcdonald, W.J., Topper, G.E., Mcmahon, M., Patton, W., Merrick, E., Merton, R.K., Kendall, P.L., Morgan, D.L., Morningstar, M.E., Turnbull, A.P., Turnbull, H.R., Rinne, M.G., Smith, M.W., Spethmann, B., Stanton, B.F., Aronson, R., Borgatti, S., Galbraith, J., Feigelman, S., Turner, S., Vaughn, S., Schumm, J.S., Sinagub, J., Wight, D., Greene, S. and Hogan, D. Exploring Children's Views through Focus Groups In: S. Greene and D. Hogan, eds. Researching Children's Experience [Internet]. Sage; 2005. Available from: https://dx.doi.org/10.4135/9781849209823.

4. O'Kane C. Review of children's participation in humanitarian programming [Internet]. London, United Kingdom; 2013. Available from: https://resourcecentre.savethechildren.net/document/review-childrens-participation-humanitarian-programming/
5. Bennouna, C., Mansourian, H. and Stark, L. Ethical considerations for children's participation in data collection activities during humanitarian emergencies: A Delphi review. Conflict and Health. 2017;11(5).
6. Thomas, N.P. and O'Kane, C. 1998. The ethics of participatory research with children. Children & Society. 1998;12:336–348.
7. Lansdown, G. and O'Kane, C. A toolkit for monitoring and evaluating children's participation. Booklet 3 [Internet]. 2014. Available from: https://resourcecentre.savethechildren.net/node/8080/pdf/me_toolkit_booklet_3_low_res1.pdf.
8. Finch, H. and Lewis, J. Focus Groups In: J. Ritchie and J. Lewis, eds. Qualitative Research Practice - A Guide for Social Science Students and Researchers. Sage, 2003;170–198.
9. Jones, L. Responding to the needs of children in crisis. International Review of Psychiatry. 2008;20(3):291–303.
10. Feinstein, C., Fyrk, K., Gezelius, H., Heiberg, T., Jareg, E., Karkara, R., Modig, C., Nilsson, M., Sheth, A. and Stevenson, S. So You Want to Involve Children in Research? [Internet]. 2004. Available from: https://www.savethechildren.org.uk/content/dam/global/reports/education-and-child-protection/so-you-want-to-involve-children-in-research.pdf.

11. Berman G, Hart J, O'Mathúna D, Mattellone E, Potts A, O'Kane C, et al. What We Know about Ethical Research Involving Children in Humanitarian Settings An overview of principles, the literature and case studies, Innocenti Working Paper No. 2016-18 [Internet]. Florence, Italy; 2016. Available from: https://www.unicef-irc.org/publications/849-what-we-know-about-ethical-research-involving-children-in-humanitarian-settings-an.html
12. Eldén, S. Inviting the messy: Drawing methods and 'children's voices'. Childhood. 2013;20(1):66–81.
13. Literat, I. 'A pencil for your thoughts': Participatory drawing as a visual research method with children and youth. The International Journal of Qualitative Methods. 2013;February.
14. Schenk, K. and Williamson, J. Ethical Approaches to Gathering Information from Children and Adolescents in International Settings: Guidelines and Resources [Internet]. 2005. Available from: https://www.popcouncil.org/uploads/pdfs/horizons/childrenethics.pdf.

A11 Manuscript 4 S2 Supporting Information: Data on sessions held in Cox's Bazar

S2 Table 1 Story Book sessions held in Cox's Bazar

Session reference	**CB 1**	**CB 2**	**CB 3**	**CB 4**	**CB 5**	**CB 6**	**CB 7**	**CB 8**
Location	Camp 8E	Camp 8E	Camp 8E	Camp 8E	Camp 7	Camp 7	Camp 7	Camp 7
Participant gender	Boys	Girls	Girls	Boys	Boys	Girls	Boys	Girls
Participant age in years	5 to 7	8 to 11	5 to 7	8 to 11	8 to 11	8 to 11	5 to 7	5 to 7
Number of participants	7	7	6	6	6	6	6	6
Duration in minutes	131	115	50	71	155	135	131	141

S2 Table 2 Answers given* on how the Hero feels after self-wetting

Session reference	**CB 1**			**CB 2**			**CB 3**			**CB 4**			**CB 5**			**CB 6**			**CB 7**			**CB 8**			**Totals**			
Location**	**P^**	**B**	**S**	**P^**	**B**	**S**	**P^**	**B**	**S**	**P^**	**B**	**S**	**P^**	**B**	**S**	**P**	**B**	**S**	**P**	**B**	**S**	**P**	**B**	**S**	**P**	**B**	**S**	**All**
Unhappy / won't feel good / feel bad / sad / upset / crying		F	C		C	C		C	C		C	C		F	C	C	C	C	C	C		C	C	C	3	8	7	18 C:16 F:2
Ashamed		C						C	C						C	C	F	C			C	C	C	C	2	4	5	11 C:10 F:1
Restless / tense											C			C			C	C	C	C	C	C	C	C	2	5	3	10

Session reference	CB 1			CB 2			CB 3			CB 4			CB 5			CB 6			CB 7			CB 8			Totals			
Location**	**P^**	**B**	**S**	**P^**	**B**	**S**	**P^**	**B**	**S**	**P^**	**B**	**S**	**P^**	**B**	**S**	**P**	**B**	**S**	**P**	**B**	**S**	**P**	**B**	**S**	**P**	**B**	**S**	**All**
																												C:10 F:0
Afraid / scared					F	F		F			F				F					F				C	0	4	3	7 C:1 F:6
Annoyed / angry			C			C					C			C			C			C	C				0	4	3	7 C:6 F:1
Other (hot, thinking, good, happy)		C									C			C					C				C		1	4	0	5 C:5 F:0
Discomfort / Uncomfortable / Feel pain		C			C									F											0	3	0	3 C:2 F:1
Embarrassed					F	C																		C	0	1	2	3 C:2 F:1
Hurt (by being laughed at / teased)			C						C															C	0	0	3	3 C:3 F:0

Session reference	CB 1			CB 2			CB 3			CB 4			CB 5			CB 6			CB 7			CB 8			Totals			
Location**	**P^**	**B**	**S**	**P^**	**B**	**S**	**P^**	**B**	**S**	**P^**	**B**	**S**	**P^**	**B**	**S**	**P**	**B**	**S**	**P**	**B**	**S**	**P**	**B**	**S**	**P**	**B**	**S**	**All**
Troubled / worried											C	C				C									1	1	1	3 C:3 F:0
Shy		F			C																				0	2	0	2 C:1 F:1
Totals																												**72** **C:59** **F:13**

*Answers given in sessions. ‘C’ indicates answer first provided by a child. ‘F’ indicates answer first provided by a facilitator.

**Location: How the hero feels after self-wetting at play (‘P’: Activity 2); home in bed (‘B’: part 1 of Activity 3); and at school (‘S’: part 2 of Activity 3).

^Session did not complete the activity.

S2 Table 3 Answers given* on reactions to the Hero after self-wetting

Session reference	CB 1		CB 2		CB 3		CB 4		CB 5		CB 6		CB 7		CB 8		Totals		
Location**	**B**	**S**	**B**	**S**	**B**	**S**	**B**	**S**	**B**	**S**	**B**	**S**	**B**	**S**	**B**	**S**	**B**	**S**	**Total**
Unhappy / won't feel good / feel bad / sad / upset / crying	F		C	C	C	C	C	C	C		C	C	C		C		8	4	12 C:11

Session reference	**CB 1**		**CB 2**		**CB 3**		**CB 4**		**CB 5**		**CB 6**		**CB 7**		**CB 8**		**Totals**		
Location**	**B**	**S**	**B**	**S**	**B**	**S**	**B**	**S**	**B**	**S**	**B**	**S**	**B**	**S**	**B**	**S**	**B**	**S**	**Total**
																			F:1
Annoyed / angry	F		C	C	F	F	C	C	C		C		C	C			7	4	11 C:8 F:3
Beat			C		C						C		C	C	C	C	5	2	7 C:7 F:0
Restless / tense					F		C	C			C		C		C		5	1	6 C:5 F:1
Scold / insult / tease					C				C	C			C	C		C	3	3	6 C:6
Troubled / worried / disturbed			F		C		C	C	C	C							4	2	6 C:5 F:1
Have to wash clothes / pati (mattress)	C								C		C				C		4	0	4 C:4
Other (thinking / happy / asked to bring Father / sent home)			C								F			C		C	2	2	4 C:3 F:1

Session reference	**CB 1**		**CB 2**		**CB 3**		**CB 4**		**CB 5**		**CB 6**		**CB 7**		**CB 8**		**Totals**		
Location**	**B**	**S**	**B**	**S**	**B**	**S**	**B**	**S**	**B**	**S**	**B**	**S**	**B**	**S**	**B**	**S**	**B**	**S**	**Total**
																			C:3 F:0
Ashamed				C		C										C	0	3	3 C:3 F:0
Discomfort / Uncomfortable	C																1	0	1 C:1 F:0
Embarrassed								C									0	1	1 C:1 F:0
Hurt / feel pain			C														1	0	1 C:1 F:0
Totals																			**62** **C:55** **F:7**

*Answers given in sessions. ‘C’ indicates answer first provided by a child. ‘F’ indicates answer first provided by a facilitator.

**Location: Reactions to the hero self-wetting at home in bed (‘B’: part 1 of Activity 3); and at school (‘S’: part 2 of Activity 3).

S2 Table 4 Answers given* when asked why the Hero wet the bed

Session reference	**CB 1**	**CB 2**	**CB 3^**	**CB 4^**	**CB 5**	**CB 6**	**CB 7**	**CB 8**	**Total**
Drank too much water	C				C	C	C	C	5 C:5 F:0
Dreaming	F	C			C	C		C	5 C:4 F:1
Couldn't control / didn’t know	C				C	C		C	4 C:4 F:0
Couldn't reach the toilet (too far)					C	C	C	C	4 C:4 F:0
Couldn't wake-up	C						C	C	3 C:3 F:0
Didn't go before bed						C		C	3 C:2

Session reference	CB 1	CB 2	CB 3^	CB 4^	CB 5	CB 6	CB 7	CB 8	Total
									F:0
No light on way to / in toilet							C	C	2 C:2 F:0
Scared to go outside	F					C			2 C:1 F:1

*Answers given in sessions. ‘C’ indicates answer first provided by a child. ‘F’ indicates answer first provided by a facilitator.

^Session did not complete the activity.

S2 Table 5 Answers given* when asked how the Hero could stop wetting the bed

Session reference	CB 1	CB 2	CB 3	CB 4	CB 5	CB 6	CB 7	CB 8	Total
Drink less water	C	C	C	C	C	C		C	7 C:7 F:0
Use the toilet before bed	C	C	F	C	C	C	C		7 C:6 F:1

Build a latrine outside the house / closer to house					C	F	C	C	4 C:3 F:1
Call mother to be taken to the latrine	C		F	C					3 C:2 F:1
Go with a lamp / Have a light in toilet	C					C		C	3 C:3 F:0
Other (Beaten / eat less rice / toilet after waking)				C		C	C		3 C:3 F:0

*Answers given in sessions. ‘C’ indicates answer first provided by a child. ‘F’ indicates answer first provided by a facilitator.

A12 Manuscript 4 S3 Supporting Information: Recommendations

Recommendation 1: Reduce the number of activities

In Adjumani District some of the Story Book sessions ran over the intended 90 minutes (excluding play breaks) even though the suggested verbal discussions did not take place. In Cox's Bazar all but two (CB3 and CB4) of the sessions took longer than 90 minutes, and CB3 and CB4 may only have been shorter because they did not discuss why the hero may have wet themselves. When designing the Story Book session the RT felt that 90 minutes was the maximum time that children aged five to eleven should be asked to participate, and indeed there were signs in both contexts that the children became tired and lost concentration at times. This suggests that the agenda needs to be modified to reduce the time needed.

Facilitators in Adjumani District provided a workbook to order and focus the activities (by providing drawing prompts on each page), but without such a workbook there was confusion in Cox's Bazar about the purpose of Activity 2. Activity 1 (co-create a hero; draw the hero playing) was completed without issue, but most facilitators then moved on to explain that the hero had woken-up to find that they had wet themselves and asked the children to draw how the hero was feeling. This was the intended focus of Activity 3, and so for some groups this became Activity 3, whereas for others (CB3 and CB4 for example) the questions were repeated when they moved to Activity 3. The intention of the separate activities was to explore if the hero reacts differently after wetting themselves at different times (when playing, during the night, and at school); and to explore the different reactions of family and community members to the self-wetting (being friends when playing, caregivers at home, and teachers at school). In practice, subtleties in verbal responses in Cox's Bazar were not detected across the different scenarios and the reactions of friends were often included when exploring self-wetting at school.

Given the confusion found regarding Activity 2 and as the sessions tended to run longer than the intended 90 minutes, it is therefore recommended that the agenda be adjusted (Table S2SI1). It is also suggested that groups use a workbook to guide the children through the activities (also see Recommendation 2). Verbal discussion options have been modified as per suggestions in Adjumani District that they may be better placed at the end of the session once the participants feel more comfortable, and to encourage the generation of ideas to improve humanitarian programmes.

Table S3 Table 1 Changes proposed to the Story Book session agenda

Agenda item	**Detail**
Activity 1: Co-creating a hero	The facilitator supports the group to create a main character, or 'hero', for their Story Book. The children are asked to choose a gender, age, name, who the hero lives with, the hero's favourite animal etc. The facilitator draws the hero as guided by the children.
Activity 2: Introducing the idea of self-wetting	The children are asked to draw the hero doing an activity that makes them feel happy, for example playing football. The facilitator then explains that after playing the hero goes home to bed, but wakes to find that they have wet themselves. The children are asked to draw what the hero does now. The children are then asked to draw what the hero's caregiver does when they find that the hero has wet the bed. *Verbal discussion options:* Reasons why the hero wet themselves (and ideas for improving the day of the hero if the facilitator chooses not to do Activity 3).
Activity 3: Exploring a further self-wetting episode	*The facilitator may choose not to do this activity depending on the time taken to complete Activities 1 and 2.* The facilitator explains that the hero has now gone to school and wets themselves there. The children are asked to draw what the hero now does. The children are then asked to draw what the hero's teacher and friends do when they find out that the hero has wet themselves. *Verbal discussion options:* Reasons why the hero wet themselves (if not already discussed) and ideas for improving the day of the hero

Recommendation 2: Simplify the drawing activities

The children (and at times, the facilitators), struggled to draw the emotions of the hero and the caregiver and/or teacher. The activities have been updated to ask the children to draw activities rather than emotions (Table S2SI1). It is also recommended that a workbook is provided for each child, with a page per activity that includes drawing

prompts. This could be outlines, as successfully used in Adjumani District, and/or a series of culturally appropriate emojis which the children can indicate as being appropriate (for example, by circling). These could also be referred to if needed to support any verbal discussions. The emojis provided should include a range of activities and emotions so that they do not guide the children to a specific answer, but not so many that the children are overwhelmed. Using such prompts may also support interpretation of the drawings by researchers to ensure that subsequent programming recommendations are appropriate.

Recommendation 3: Use the Story Book sessions to normalise self-wetting

There may be an opportunity to better use the sessions to educate children on key messages such as how prevalent self-wetting is, and the fact that most children grow out of the condition. Such information could help to reassure any children experiencing self-wetting and also help to lessen any stigma associated with self-wetting. As suggested in Adjumani District these could even be incorporated into songs or stories to be used as ice-breakers. Similarly, at the end of the session the facilitator could provide the name of someone as a first contact to getting support for self-wetting in the home. The children could be advised that they can approach this person themselves, tell the name to their caregiver, and/or tell anyone they know that may need such support.