

# References on supporting people with incontinence in humanitarian and low- and middle-income countries (LMICs)

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**Prepared by** - This document has been compiled by members of an informal international cross-sectoral email group focused on learning how best to work with and support people with incontinence in humanitarian and low- and middle-income contexts.

**Associated documents** - This document is one of a set of four, being:

- a) Guidance
- b) Summary guidance four-pager
- c) Case studies
- d) References (this document)

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# 1. Introductory and overview documents

## Compiled summary documents

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

LMIC-Incontinence-email-group: other guidance - related humanitarian contexts and LMICs (2019):

- *Summary guidance*
- *Case studies*
- *References*

## Introductory overviews

- Barrington, D, J. and Culmer, P (2017) *Why we need to talk about incontinence [online]*, The Conversation. Available at: <http://theconversation.com/why-we-need-to-talk-about-incontinence-86080>
- Giles-Hansen, C (2015) *Hygiene needs of incontinence sufferers; How can water, sanitation and hygiene actors better address the needs of vulnerable people suffering from urine and / or faecal incontinence in low- and middle-income countries [online]*, WaterAid and SHARE Research Consortium. Available at: <http://www.communityledtotalsanitation.org/resource/hygiene-needs-incontinence-sufferers>
- 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. Pla Cordero, R. Cavill, S. and House, S. (2016) 'Incompetent at incontinence - why are we ignoring the needs of incontinence sufferers? [online]' *Waterlines*, 35(3). Available at: <https://www.developmentbookshelf.com/doi/10.3362/1756-3488.2016.018>
- House, S (2016) Considerations for selecting sanitary protection and incontinence materials for refugee contexts, UNHCR. Available at: <http://wash.unhcr.org/download/considerations-for-selecting-sanitary-protection-and-incontinence-materials-for-refugee-contexts/>
- International Continence Society (2015), *Factsheets. A background to urinary and faecal incontinence [online]*. Available at: <https://www.ics.org/folder/news-and-publications/ics-factsheets/d/ics-factsheets-2015>
- Rosato-Scott, C. A. and Barrington, D (2018) 'Incontinence in Zambia: Initial investigation into the coping strategies of sufferers and carers' [online], *Waterlines*. 37(3):190-206. Available at: <https://www.developmentbookshelf.com/doi/full/10.3362/1756-3488.18-00012>
- UNHCR (2016) *Overview: Menstrual Hygiene & Incontinence Management in Refugee Contexts*. Available at: <http://wash.unhcr.org/download/overview-of-menstrual-hygiene-incontinence-in-emergencies/>

## Practical guidance overview

- USAID/WASH Plus Project (2014) *Integrating safe water, sanitation and hygiene into HIV programmes, A training and resource pack for Uganda, November 2014 [online]*. Available at: [www.washplus.org/sites/default/files/uganda-wash\\_hiv.pdf](http://www.washplus.org/sites/default/files/uganda-wash_hiv.pdf)
- World Vision and CBM Australia (2018) *Learning from experience: Guidelines for locally sourced and cost-effective strategies for hygiene at home for people with high support needs [online]*. Available at: [https://www.cbm.org.au/wp-content/uploads/2019/02/CBM\\_WV\\_hygiene-at-home.compressed.pdf](https://www.cbm.org.au/wp-content/uploads/2019/02/CBM_WV_hygiene-at-home.compressed.pdf)

## Websites - overview

- Continence Foundation: <http://www.continence-foundation.org.uk/>
- Continence Foundation of Australia: <https://www.continence.org.au/>
- International Children's Continence Society: <http://i-c-c-s.org>
- International Continence Society: <https://www.ics.org/>
- International Continence Society Developing World Committee: <https://www.ics.org/committees/developingworld>

## **2. Research, evidence, realities of incontinence - LMICs**

### Humanitarian

- Alam, S (2019) *Older people and people with disability inclusion gaps*, [PowerPoint], HelpAge International: Cox's Bazar, Bangladesh. Available at: <https://drive.google.com/file/d/152MPOV1123d1hsA5TYqWFzK70smGBAax/view?usp=sharing>
- Amnesty International (2019) *"Fleeing my whole life" Older people's experience of conflict and displacement in Myanmar [online]*. Available at: <https://www.amnesty.org/en/latest/campaigns/2019/06/fmwl-myanmar-older-people/>
- HelpAge (2018) *Needs and Gap Analysis Older Refugee Population Cox's Bazar, Bangladesh*. Available at: <https://drive.google.com/file/d/1ONvnk89W7BsqiM-h6VQbFI2S7tUB2QzM/view?usp=sharing>
- House, S (2019) *Strengthening the humanity in humanitarian action in the work of the WASH sector in the Rohingya response; Gender, GBV and inclusion audit of the work of the WASH sector and capacity development assessment [online]*, UNICEF and the WASH Sector: Cox's Bazar. Available at:
  - Main report: <https://drive.google.com/file/d/1DFRrH-DnKHc5zz1aMgYa2ieNDI3SoDrh/view?usp=sharing> (refers to incontinence in Cox's Bazar mainly in section 5.2.10 – pages 70 to 75; but other sections also include relevant information such as on the situation of older people and people with disabilities in section 5.1.1 – pages 24 – 29; and on challenges for cross-sectoral coordination in section 6.3 – pages 107 – 109)

- Summary: [https://drive.google.com/file/d/1Ko5H6UYwfS\\_J3eN9zBxerTLyaVC9VuVC/view?usp=sharing](https://drive.google.com/file/d/1Ko5H6UYwfS_J3eN9zBxerTLyaVC9VuVC/view?usp=sharing)
  - Recommendations for WASH sector roadmap: [https://drive.google.com/file/d/1Nq0ZQyJo\\_xOtGdhaMueakBGj8kSRKvVX/view?usp=sharing](https://drive.google.com/file/d/1Nq0ZQyJo_xOtGdhaMueakBGj8kSRKvVX/view?usp=sharing)
  - Annexes: <https://drive.google.com/file/d/1yj2djh0-QKOe9Y9airQy42bTudVrODX0/view?usp=sharing>
  - Presentation: <https://drive.google.com/file/d/1Bzc1P-4BRA39WilPB0fgFLqXZyHjAyib/view?usp=sharing>
- Rosato-Scott, C (2019) *Emergency sanitation for children with urinary incontinence*, [Poster], Postgraduate Conference, April 2019, University of Leeds, United Kingdom. Available at: <https://drive.google.com/file/d/1E5OI0o7R2oXz1Uqzn12t44-sKqDzINE/view?usp=sharing>

### **Development and general**

- Ali, H.S., Lakhani, N.A. and Sarwar, N.G (2013) Urinary incontinence three months after delivery; prevalence and risk factors [online], *Professional Med J*, 20(4), pp.530-536. Available at: <https://pdfs.semanticscholar.org/ab0a/dbccb0c1cb21c44c95ddcf804535b62b6676.pdf>
- Ansari, Z (2017) *Understanding the coping mechanisms employed by people with disabilities and their families to manage incontinence in Pakistan*, MSc Project report: London School of Hygiene and Tropical Medicine. Available at: <https://drive.google.com/file/d/13sj4trd2XqhKNbzRXrDu3WszuYthg7b5/view?usp=sharing>
- Scott, C A (2017) *Incontinence in Zambia: Understanding the coping strategies for sufferers* (Blog) [online], IMPRESS network: University of Leeds. Available at: <http://impress-network.com/zambia-blog/>
- Scott, C. A (2017) *Incontinence in Zambia: Understanding the coping strategies of sufferers and carers* [online], MSc Thesis: Cranfield University. Available at: <http://impress-network.com/wp-content/uploads/2017/10/Claire-Scott-Thesis-Incontinence-in-Zambia-1.pdf>

## **3. Accessibility to WASH**

### **Papers and documents:**

- Jones, H.E. and Reed, R.A (2005) *Water and sanitation for disabled people and other vulnerable groups: Designing services to improve accessibility* [online], WEDC: Loughborough University. Available at: <https://www.susana.org/en/resources/library/details/2218>
- Jones, H. E. and Wilbur, J (2014) *The compendium of accessible WASH technologies* [online], WEDC, WaterAid, and SHARE Research Consortium. Available at: [http://www.wateraid.org/~/\\_/media/Publications/Compendium%20of%20accessible%20WASH%20technologies/Compendium-of-accessible-WASH-technologies-low-res.pdf](http://www.wateraid.org/~/_/media/Publications/Compendium%20of%20accessible%20WASH%20technologies/Compendium-of-accessible-WASH-technologies-low-res.pdf)

- World Vision and CBM Australia (2018) *Learning from experience: Guidelines for locally sourced and cost-effective strategies to modify existing household toilets and water access [online]*. Available at: <https://www.cbm.org.au/wp-content/uploads/2019/02/CBM-World-Vision-Home-WASH-modifications-Sri-Lanka.pdf>

### **Websites:**

- CBM online app link to guidance for WASH in emergencies: <https://hhot.cbm.org/>
- CBM WASH resource page including links to guidance notes, case studies, and disability inclusive WASH training packages: <https://www.cbm.org.au/our-resources/wash/>
- CSWASH project (other disability inclusive WASH resources that may be useful): [http://www.cswash-fund.org/shared-resources/tools?keys=&field\\_resource\\_topic\\_tid%5B%5D=49&=Submit&sort\\_bef\\_combine=field\\_publication\\_date\\_value+DESC](http://www.cswash-fund.org/shared-resources/tools?keys=&field_resource_topic_tid%5B%5D=49&=Submit&sort_bef_combine=field_publication_date_value+DESC)
- DID4all resources on disability and WASH (an aid donor-focused resource collection maintained by CBM): <https://www.did4all.com.au/ResourceTheme.aspx?4cc97d67-3134-4c08-8290-fa7a0509dda>
- Disability inclusive WASH library maintained by WaterAid Australia: <http://www.inclusivewash.org.au/resource-library-people-with-disabilities>
- WaterAid, Undoing Inequity pages: <https://washmatters.wateraid.org/publications/undoing-inequity>
- WEDC resources on disability and WASH: <https://wedc-knowledge.lboro.ac.uk/collections/equity-inclusion/disability-wash.html>

## **4. Fistula care**

### **Presentations, papers and documents**

- Akter, F (2019) *Incontinence in female genital tract, Hope Foundation Hospital, Ramu, Cox's Bazar, Bangladesh, PPT*. Available at: <https://drive.google.com/file/d/1wvRPn6jprw60r7-sEV-kdG4J9R6W8FYB2/view?usp=sharing> (After a general introduction focusses mainly on fistula)
- Akter, F (2019) *Fistula activities in Hope Hospital, Hope Foundation Hospital, Ramu, Cox's Bazar, Bangladesh, PPT*. Available at: [https://drive.google.com/file/d/1tBwG\\_Z6FLUvkhmfNRD0b2MRL9j40TVTh/view?usp=sharing](https://drive.google.com/file/d/1tBwG_Z6FLUvkhmfNRD0b2MRL9j40TVTh/view?usp=sharing) (After a general introduction focusses mainly on fistula)
- East, Central, and Southern African Health Community (ECSA-HC) and Fistula Care/EngenderHealth (2012) *The prevention and management of obstetric fistula: A curriculum for nurses and midwives*. New York: EngenderHealth/ Fistula Care. Available at: <https://www.engenderhealth.org/files/pubs/fistula-care-digital-archive/3/3.1/Prevention-Management-Nursing-Curriculum-English.pdf>

- EngenderHealth (2012) *Fistula Training Strategy, Guidelines and Standards*. New York: EngenderHealth/Fistula Care. Available at: <https://fistulacare.org/wp-fcp/wp-content/uploads/pdf/Training/FistulaTrainingStrategyEngenderHealthFistulaCare070708formatted.pdf>

### **Case studies - fistula**

- EngenderHealth (2013) *Creating an enabling environment for fistula prevention and treatment in Uganda*. New York: EngenderHealth/Fistula Care. Available at: <https://www.engenderhealth.org/wp-content/uploads/imports/files/pubs/fistula-care-digital-archive/7/7.4/Uganda TWG TB ENGLISH.pdf>
- Moylan, D (2016) *The affliction destroying Afghan women's lives, A female-run clinic in Afghanistan is providing free, life changing surgery to women suffering from fistula [online]*, Aljazeera. Available at: <https://www.aljazeera.com/indepth/features/2016/05/affliction-destroying-afghan-women-lives-160516104239351.html>
- Semere, L and Nour, N (2008) 'Obstetric fistula: living with incontinence and shame', *Reviews in Obstetrics and Gynaecology*, 1(4). pp.193-197. Available at: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2621054/>

### **Websites - fistula**

- Engender Health: <https://www.engenderhealth.org/our-work/maternal/fistula/>
- Fistula Care: <https://fistulacare.org>
- Hope Hospital, Bangladesh: <https://www.hopeforbangladesh.org/hope-hospital>
- International Continence Society Obstetric fistula in the developing world: <https://www.ics.org/committees/developingworld/publicawareness/obstetricfistulaanintroduction>

## **5. Catheters, continence technologies and assistive products**

### **Papers and documents:**

- Culmer, P, Alazmani, A, Bryant, M, Mancuso, E, King, S, Mapunde, V, Jeays-Ward, K, Heron, N, Pearson, R, Vollebregt, P. F., Corner, L and Day, R (2018) 'Continence technologies whitepaper: Informing new engineering science research', *Journal of Engineering in Medicine*. pp.1-16. Available at: <https://pure.ulster.ac.uk/en/publications/continence-technologies-whitepaper-informing-new-engineering-science>
- Fader M, Cottenden A, Getliffe K, Gage H, Clarke-O'Neill S, Jamieson K, et al. (2018) Absorbent products for urinary/faecal incontinence: a comparative evaluation of key product designs. *Health Technology Assessment* 2008;12(29). [https://eprints.soton.ac.uk/189241/1/Absorbent\\_products\\_for\\_urinaryfaecal\\_incontinence.pdf](https://eprints.soton.ac.uk/189241/1/Absorbent_products_for_urinaryfaecal_incontinence.pdf)
- Huong, V. T and Hong, L. T (2006) *Intermittent Self-Catherization at Home*, Hospital of Rehabilitation and Professionals Diseases, Spinal Unit, Ho Chi Minh City and Handicap International

- Motivation Australia (2016) *Urinary Management Product Trial*, Evaluation Report (Fiji). Available at: <https://drive.google.com/file/d/11LrlaUd5uqIPJ1O2t03SFO4ZuakV7Jc8/view?usp=sharing>
- World Health Organisation (2016) *Priority Assistive Products List, Improving access to assistive technology for everyone, everywhere [online]*, WHO: Geneva. Available at: <https://apps.who.int/medicinedocs/documents/s22396en/s22396en.pdf>
- Wynedeale, Maderbacher, Khovindha et al (no date) *Bladder Management Curriculum, Training Vietnam*, Handicap International

### **Websites**

- Continence product advisor website: <https://www.continenceproductadvisor.org/> - by Southampton University
- IMPRESS Network: <http://impress-network.com/>
- WHO assistive technologies site: <http://who.int/assistivetechology>

## **6. Case studies - LMICs**

### **Perimenopausal and post-menopausal women**

- Bhakta, A. (2019) *Opening the doors to the water, sanitation and hygiene needs of women from the onset of the perimenopause in urban Ghana*. PhD Thesis, Loughborough University, Loughborough. Available at: [https://repository.lboro.ac.uk/articles/Opening\\_the\\_doors\\_to\\_the\\_hidden\\_water\\_sanitation\\_and\\_hygiene\\_needs\\_of\\_women\\_from\\_the\\_onset\\_of\\_the\\_perimenopause\\_in\\_urban\\_Ghana/8230220/1](https://repository.lboro.ac.uk/articles/Opening_the_doors_to_the_hidden_water_sanitation_and_hygiene_needs_of_women_from_the_onset_of_the_perimenopause_in_urban_Ghana/8230220/1) (Focusses on a range of issues including MHM, bathing, laundry and also, incontinence. Discussion relating to perimenopause and incontinence in depth can be found on p.190, p.223, p.250-onwards, p.255)

### **Humanitarian**

- Save the Children (2016) *Childhood under Siege – living and dying in besieged areas of Syria [online]*. Save the Children. Available at: <https://reliefweb.int/report/syrian-arab-republic/childhood-under-siege-living-and-dying-besieged-areas-syria>
- Venema, V (2015) *The unlikely sanitary pad missionary [online]*, BBC. Available at: <http://www.bbc.co.uk/news/magazine-34925238>

### **Development**

- Aljazeera (2017) *South Sudan: High rate of child birth injuries [online]*. Available at: <https://www.aljazeera.com/news/2018/05/maternal-death-rates-south-sudan-worlds-highest-180523110824332.html> (video report about fistula and incontinence in South Sudan)

- Asari, Z (2017) *Sitting across the Charpai, incontinence amongst the ultra poor [online]*, The Field Reviewer. Available at: <https://www.thefieldreviewer.com/single-post/2017/10/22/Sitting-Across-the-Charpai-incontinence-amongst-the-ultra-poor>
- 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. Available at: <https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0201860>
- Gjerde, J.L., Rortveit, G., Muleta, M. and Blystad, A (2013) 'Silently waiting to heal. Experiences among women living with urinary incontinence in northwest Ethiopia', *International Urogynecological Journal*, 24, pp.953-958. Available at: <https://www.ncbi.nlm.nih.gov/pubmed/23129246> Behind pay wall
- Strandqvist, K (2017) *Health and health matters in the later stages of life (Incontinence and Elder care) [online]*, World Health Assembly 2017: Geneva. Available at: <https://www.wsscc.org/wp-content/uploads/2017/06/Health-and-Hygiene-Across-the-Life-Course-WHA-2017-Report-final.pdf>

## 7. Documents with brief mention of incontinence - LMICs

### Humanitarian – strategic and guidance

- Age and Disability Consortium (2018) *Humanitarian standards for older people and people with disabilities [online]*, Available at: [https://reliefweb.int/sites/reliefweb.int/files/resources/Humanitarian\\_inclusion\\_standards\\_for\\_older\\_people\\_and\\_people\\_with\\_disabi....pdf](https://reliefweb.int/sites/reliefweb.int/files/resources/Humanitarian_inclusion_standards_for_older_people_and_people_with_disabi....pdf) (pp 124-134)
- Government of the People's Republic of Bangladesh, Ministry of Local Government Rural Development & Cooperatives, DPHE and Department of Disaster Management (2017) *Operational Guidelines for WASH in Emergencies – Bangladesh [online]*. Available at: [https://www.humanitarianresponse.info/sites/www.humanitarianresponse.info/files/documents/files/final\\_draft\\_wash\\_guideline\\_23feb17.pdf](https://www.humanitarianresponse.info/sites/www.humanitarianresponse.info/files/documents/files/final_draft_wash_guideline_23feb17.pdf) (incontinence or simple adaptations for accessibility - pp 107 + 115 + 120-124)
- Inter-Agency Standing Committee (2017) *Gender Handbook for Humanitarian Action [online]*. Available at: <https://interagencystandingcommittee.org/gender-and-humanitarian-action/content/iasc-2017-gender-handbook-humanitarian-action-english> (p 372, Includes the provision of non-food items including for menstruation and incontinence)
- Inter-Agency Standing Committee (2015) *Guidelines for Integrating Gender-Based Violence Interventions in Humanitarian Action [online]*. Available at: [https://gbvguidelines.org/wp/wp-content/uploads/2015/09/2015-IASC-Gender-based-Violence-Guidelines\\_lo-res.pdf](https://gbvguidelines.org/wp/wp-content/uploads/2015/09/2015-IASC-Gender-based-Violence-Guidelines_lo-res.pdf) (pp 283 and 292, discussion on discrete provision of hygiene and dignity kits and need for better access to WASH facilities for males and females who have suffered trauma due to rape and hence have incontinence)
- Sphere Association (2018) *Minimum Standards for Humanitarian Response [online]*. Available at: <https://www.spherestandards.org/handbook-2018/> (p 102, WASH Chapter - Hygiene Promotion section, Standard 1.3)

- UNHCR (2017) *WASH, Protection & Accountability*, Briefing Note. Available at <http://wash.unhcr.org/download/wash-protection-and-accountability/> (includes incontinence integrated with MHM)
- WASH Sector Cox's Bazar (2018) *WASH Sector Strategy, Cox's Bazar Rohingya Refugee response [online]*. Available at: <https://www.humanitarianresponse.info/en/operations/bangladesh/document/wash-sector-cxb-2018-strategy> (p 20)

### **Humanitarian - assessments**

- HelpAge International (2013) *Displacement and older people, The Case of the Great East Japan Earthquake and Tsunami of 2011*. Available at: <https://reliefweb.int/report/japan/displacement-and-older-people-case-great-east-japan-earthquake-and-tsunami-2011> (info on problems accessing WASH pp 3, 9, 11 and incontinence items p18)

### **Development – assessments, research**

- Caruso, B. A. Clasen, T. F. Hadley, C. Yount, K. M. Haardorfer, R. Rout, M. Dasmohapatra, M. and Cooper, H.L.F (2017) Understanding and defining sanitation insecurity: women's gendered experiences of urination, defecation and menstruation in rural Odisha, India. *BMJ Glob. Health*. 2:E000414. Available at: <https://gh.bmj.com/content/2/4/e000414>
- Choden T., Coe S., and Cheizom P (2016) *Understanding the impacts of disability on access and use of sanitation and hygiene services in rural Bhutan. A disability study report*, SNV. Available at: <http://www.snv.org/public/cms/sites/default/files/explore/download/2016-impactsofdisabilitysnvbhutan.pdf>
- WaterAid and CBM (no date) *Understanding disability and access to water, sanitation and hygiene East Sepik, Papua New Guinea*. Available at: [http://www.cswashfund.org/sites/default/files/2015\\_WaterAid\\_Situation%20Analysis%20Disability\\_WASH%20FULL%20REPORT%20PNG.pdf](http://www.cswashfund.org/sites/default/files/2015_WaterAid_Situation%20Analysis%20Disability_WASH%20FULL%20REPORT%20PNG.pdf)
- White, S. Kuper, H. Itimu-Phiri, A. Holm, R. and Biran, A (2016) A Qualitative Study of Barriers to Accessing Water, Sanitation and Hygiene for Disabled People in Malawi. *PLoS ONE*. 11(5): e0155043. Available at: <https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0155043>

### **Development - advocacy**

- Chambers, R. (2017) *Can We Know Better? Reflections for Development*, Rugby, UK: Practical Action Publishing, <http://dx.doi.org/10.3362/9781780449449>. Available at: <https://www.developmentbookshelf.com/doi/book/10.3362/9781780449449> (p 38)

### **Development - guidance**

- UNICEF, WaterAid and WSUP (2018) *Female-friendly public and community toilets: a guide for planners and decision makers [online]*, WaterAid: London, UK. Available at: <https://washmatters.wateraid.org/publications/female-friendly-public-and-community-toilets-a-guide-for-planners-and-decision-makers> (p 5)

- WSSCC (2019) *Equality and Non-Discrimination Handbook for CLTS Facilitators*, WSSCC, Geneva, Switzerland. <https://www.wsscc.org/resources-feed/equality-and-non-discrimination-handbook-for-clts-facilitators/> (includes small mentions on pages 90 and 98)

## 8. Research, evidence, realities of incontinence – Global

### Advocacy, experiences, stigma

- Barrington, D. Jasperson, L and Sale, I (2019) *Breaking the silence on women’s experiences of urinary incontinence [online]*. University of Leeds: Leeds, United Kingdom. Available at: <https://wash.leeds.ac.uk/wp-content/uploads/sites/45/2019/01/Workshop-Report-FINAL.pdf>
- 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. Available at: <https://experts.umn.edu/en/publications/breaking-the-cycle-of-stigmatization-managing-the-stigma-of-incon> Behind pay wall
- Miller, E (2017) *Why I wrote a comedy show about incontinence [online]*, The Guardian. Available at: <https://www.theguardian.com/healthcare-network/2017/aug/10/why-wrote-comedy-show-incontinence-edinburgh-fringe>
- Takahashi, K and Kitamura, Y (2016) ‘Disaster anxiety and self-assistance behaviours among persons with cervical cord injury in Japan: a qualitative study’. *BMJ*. 6:e009929. Available at: <https://bmjopen.bmj.com/content/bmjopen/6/4/e009929.full.pdf>

### Technical / medical

- 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 Nevés, 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. Available at: <https://doi.org/10.1002/nau.22751> Behind pay wall
- Buckley, B.S. and Carmela M Lapitan, 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. Available at: <https://europepmc.org/abstract/med/20541241> Behind pay wall
- Minassian, V.A. Drutz, H.P. and Al-Badr, A (2003) ‘Urinary incontinence as a worldwide problem’. *International Journal of Gynaecology & Obstetrics*. 82, pp.327-338. Available at: <https://www.ncbi.nlm.nih.gov/pubmed/14499979>
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## 9. Guidance on working with people who may be disadvantaged

- House, S (2018) *Guidance and tips for learning from people who may be most disadvantaged during the programme process*, WSSCC, Oct 2018, <https://www.wsscc.org/resources-feed/eqnd-learning-guide> (*Guidance on how to engage and communicated with people who may be particularly disadvantaged (vulnerable or marginalised) including ethics and how to do no harm*)