

Disability and humanitarian health ethics

Amongst the wide array of ethical considerations associated with humanitarian aid, questions of equity and justice loom large. Situations of crisis may result in increased solidarity within a population, as well as between communities. In other instances, crises reinforce or create divides, including increased marginalization or discrimination. Policies and practices of humanitarian organizations can also encourage mutual support and resiliency within communities, or give rise to concerns related to equity and fairness, or even reinforce stigma. A particular area of concern for humanitarian health ethics is how the needs of especially vulnerable individuals within communities are taken into account in planning and implementing relief and reconstruction efforts.

Persons with disabilities make up 15% of the world's population and have been described as the world's largest minority.¹ They and their families are more likely to be poor compared to others living in the same communities. Persons with disabilities also tend to be in poorer health, have fewer work opportunities, and be less likely to attend school. In many contexts, they experience discrimination. During a humanitarian crisis, including disaster, war or disease outbreak, they are also susceptible to experience a range of harms including being left behind during evacuation, excluded from services, separated from caregivers, or losing their adaptive aids.

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Debris lines the streets of [Tacloban](#), [Leyte island](#). This region was the worst affected by the typhoon Haiyan, Philippines 2013. Navigating environments such as these with pre-existing mobility issues is nearly impossible.

(Photo: Eoghan Rice - Trócaire / Caritas:

https://commons.wikimedia.org/wiki/File:Tacloban_Typhoon_Haiyan_2013-11-14.jpg)

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During some disasters, persons with disabilities have also been excluded from shelters and registries.² For these reasons, it has been asserted that “[i]n humanitarian emergency situations, persons with disabilities are amongst the most vulnerable groups of society and tend to be disproportionately affected by the impacts of disasters.”³

The importance of including persons with disabilities in disaster planning, and attending to their needs in relief and reconstruction efforts, has been widely recognized, and has been included in standards and guidance documents related to humanitarian aid.^{2,3,4} The responsibilities of states to ensure the protection and safety of persons with disabilities during humanitarian crises has also be inscribed in the UN Convention on the Rights of Persons With Disabilities.⁵ Despite these commitments, challenges remain in putting these commitments into action and disability largely remains a peripheral issue in humanitarian aid.

A range of ethical issues associated with disability and humanitarian aid warrant careful scrutiny. As suggested by Maria Berghs’ contribution to *Reflections*, two central questions are why is disability usually absent from humanitarian discourse, and how can this situation be remedied? Other questions can be asked, including: What are the responsibilities of aid organizations to make their programs inclusive for individuals with a wide range of disabilities (even when doing so requires additional resources in a situation of severe resource limitation)? What consideration should be accorded to disability in decisions related to prioritization and triage during a crisis? What role(s) ought international humanitarian relief agencies play in advocating for the needs of persons with disabilities who lack access to services or recognition of their rights, or when they experience discrimination in their own communities? How might considering all people with disabilities as a ‘vulnerable group’ gloss over important differences between individuals, or exclude some people whose disabilities are not as visible? When organizations provide life saving interventions (e.g. amputations or stabilization of spinal cord injuries) during a crisis, do they have obligations to ensure that rehabilitation is available for these individuals who survive yet experience significant disabilities? Scholars and others engaged in humanitarian health ethics can play an important role by investigating these and other questions related to disability and humanitarian crises, ideally through collaborations with persons with disabilities.

Persons with disabilities are especially likely to experience harms or be wronged during a humanitarian crisis. The needs of these individuals, and the ways they are addressed by humanitarian organizations, are thus crucial concerns for humanitarian health ethics. [References one page 10.]

Till further conversations,

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In Focus: Stephanie Nixon

Stephanie is a physiotherapist who has been an HIV activist and researcher for 20 years. She completed her BHSc in Physiotherapy at McMaster University in 1996, and then moved to the University of Toronto for her MSc (Rehabilitation Science, 2000) and PhD (Public Health and Bioethics, 2006). Stephanie's PhD used a critical public health ethics lens to examine the Government of Canada's international response to HIV. She then conducted her post-doc at the Health Economics and HIV/AIDS Research Division (HEARD) at the University of KwaZulu-Natal in South Africa from 2006-2008.



Photo credit: <http://www.physicaltherapy.utoronto.ca/news-events/stephanie-nixon-receive-2015-faculty-medicine-graduate-teaching-award>

She is now an Associate Professor in the Department of Physical Therapy and Dalla Lana School of Public Health, and Director of the International Centre for Disability and Rehabilitation, at the University of Toronto. Recently, she was awarded the 2015 Faculty of Medicine Graduate Teaching Award for Early Career Excellence in Graduate Teaching and Mentorship for Physical Therapy at the University of Toronto.

Currently, she leads two programmes of research: (1) HIV, disability and rehabilitation in Sub-Saharan Africa and Canada, and (2) education scholarship on how to develop critical analysis skills among health care providers (with a particular interest in racism, ableism and colonization).

**Stephanie is co-editing with Matthew Hunt, a special issue of
Physiotherapy Canada:**

Global Health, Disability, and Rehabilitation: Implications for Physiotherapy

Papers are being accepted until February 1, 2016.

Disability and humanitarian healthcare ethics: Why a disparate field of research?

By Maria Berghs

In the last few years, there has been a lot of emphasis on 'global risks',¹ for instance in terms of impact of climate change and connection to conflicts, pandemics and disasters. Humanitarian discourses too seem to be increasingly focused on understanding risks and their containment for a collective (bio) security. The changing relationship between conflict, destabilisation and violence to migration, also seems to reveal a striking pattern, in that people are moving, in an often dangerous and sometimes illegal trajectory, from the global south to north. While anxieties have been raised in some Western states about the impact of this migration, most refugees are still located in the global south.² Humanitarian aid is now trying to keep up with this increased mobility but has been slow to adapt, leading to human rights abuses, creation of impairments and deaths.³ Similarly, our conceptions of 'borders' are altering to accommodate the shifts in forced migration patterns and the social, political, economic, cultural and virtual networks that now exist to govern these new sites, for example in terms of biometrics or illegal trafficking.^{4,5} There is also a link between impacts of new global risks, (bio) security and the use of new virtual technologies of surveillance.

Within this broad and rapidly changing field, disability is often conceptualised in terms of individual physical vulnerability and specialised need for disability services, for example, in refugee camps. Often research will focus on how the United Nations Convention on the Rights of Persons with Disabilities (CRPD) is being upheld in humanitarianism. There are two striking things about this; firstly, while those issues are important, I argue that they are out of touch with current research in disability studies, medical anthropology, science and technology studies and healthcare ethics. Secondly, disability is associated with public health risk, burden or cost located within the, typically, southern body. Agency and information from people themselves in their cultural terms seems lost.

Western norms and values of how disability is understood as bodily impairment thus travel and can impose this identity where it may not have existed before, for example, in terms of disablement or stigma. It is also noteworthy that while disability is mostly absent from mainstream humanitarian discourse, it has gathered more political impetus when analyzed alongside other biosocial or genetic identities in medical humanitarianism. When speaking of impact of aging, chronic conditions or mental health within refugee populations, disability becomes an economic 'currency', for example, in terms of disability adjusted life year (DALY) or global burden of disease. A delimited medical humanitarianism, or the absence of aid, is never examined in terms of the risk this poses for creating impairment and evidence in this direction are rarely connected, unless it is about mortality.

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We witnessed this strange state of affairs during the Ebola epidemic, where risk and its containment became associated with West African states and people but disability was absent. It was absent in terms of, recognizing: (1) how the epidemic would affect people who had impairments; (2) how mortality and morbidity were increasing in the local population because of lack of health care access within collapsing systems; (3) how stigma became linked to Ebola through medical humanitarianism that also initially prioritised white lives and, (4) how disability was linked to impact of Ebola on communities and survivors in lack of long term planning of robust health and social care systems. Is the fact that 'Ebola-survivors' with chronic impairments and mental health issues are currently participating in research and interventions, linked to why they have not been categorised as 'disabled'?

"...the absence of aid is never examined in terms of the risk this poses for creating impairment..."

Current debates ethically question why neglect is happening and the implications on equity of not thinking through the inclusions and exclusions of 'disability' and how it is counted in humanitarian aid, activism and research evidence. Humanitarian debates now try to understand ascriptions of discourses of 'risk' by focusing on creation of inequalities. For example, in terms of how the global economic system ties into structural creation of impairment in southern states and people. They are also examining how disablement is linked to the creation of biosecurity and use of biometric data in the global south; raising important issues linked to an uneven ethical governance and data protection. The fact that the flow of information is again going in a certain direction raises questions about how and why this information is being gathered through, for example, fingerprints from refugees in camps or iris scans at border crossings. Is this really to aid or to ensure security of fragile and disabled states? How does this connect to a colonial past, war on terror, economic governance and neoliberal citizenship? What ownership, advocacy and education do local people themselves have in these contexts about biometrics? Should this be a humanitarian concern?

At the same time as there has been an upsurge in the gathering of biometric data, there has also been an increase in genetic and genomic data collection in the global south, for instance, linked to global mental health to understand conditions like schizophrenia. The connections of this new bio-banking, humanitarianism and links to disability identity remain unexplored in global bioethics. In many ways, the above global challenges linked to humanitarian healthcare ethics, indicate a need to understand the complexity of disability on myriad levels of ethical analysis; from the global to the now (bio)local. A more inclusive disability should now urgently become a part of global humanitarian healthcare (bio) ethics. [References one page 10.]

Dr. Maria Berghs works as a Research Fellow in Health Sciences at the University of York in the United Kingdom. maria.berghs@york.ac.uk

New Research Study Seeking Participant



Researchers' experiences of ethics during disaster research in low-resource settings

We are conducting a study in order to understand:

- 1) What the moral experience of researchers operating in post-disaster settings is
- 2) How researchers operating in post-disaster settings use existing ethics guidelines
- 3) To what extent existing resources help researchers work through the uncertainty they face while conducting research in post-disaster settings

We are seeking members of research teams who have experience conducting disaster research in low-resource settings who would be willing to participate in a 45-90 minute interview.

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For more information, please contact Mr. Renaud Boulanger, M.Sc. candidate
renaud.boulanger@mail.mcgill.ca



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reflecting on ethical practice



Photo courtesy of
Lynda Redwood-Campbell

Humanitarian

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A New Study!

Ethics in Humanitarian Healthcare Practice and Policy During Acute Crisis Response in Lower and Middle Income Countries

To better understand ethical issues arising from health-related humanitarian aid in settings of disaster, conflict, or complex emergencies.

We seek participants for interviews!

Interviews will be conducted by phone, by Skype, or in person at a time convenient for you, and will take approximately 45-90 minutes.

Confidentiality: All personal information will be removed from the data. Participants will receive a small honorarium.

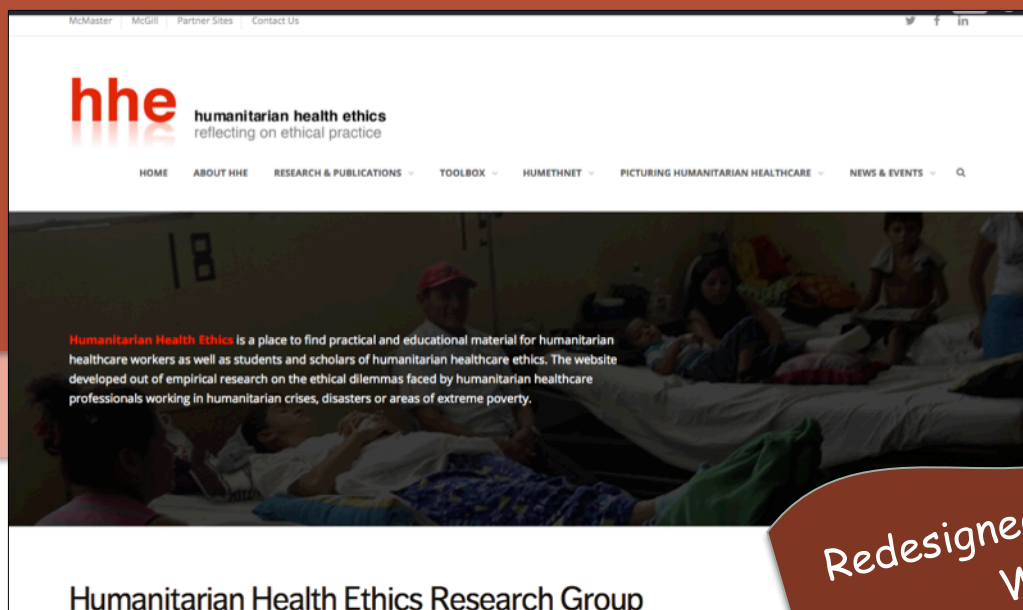
1. Policy personnel: Individuals with experience in writing, implementing or evaluating policies in acute humanitarian emergencies.
2. Healthcare fieldwork: Individuals with experience as part of the humanitarian healthcare team during acute humanitarian emergencies.

For more information please contact:

Policy personnel: Leigh-Anne Gillespie (gilleslb@mcmaster.ca)

Health care fieldwork: John Pringle (john.pringle@mcgill.ca)

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As websites are 'living' resources, by all means please contact us if there are suggestions or additions you would like to see:
humethnet@gmail.com.



Just released:

Handicap International's study report on *Disability in humanitarian context*.

Available at:

http://www.handicap-international.us/inclusion_resources

Fast Facts From the Report:

- 54% of respondents with disabilities state they have experienced a direct physical impact, sometimes causing new impairments.
- 27% report that they have been psychologically, physically or sexually abused. Increased psychological stress and/or disorientation are other effects of the crisis for 38% of the respondents with disabilities.
- Three quarters of the respondents report that they did not have adequate access to basic assistance such as water, shelter, food or health
- 85% of humanitarian actors responding to the survey recognise that persons with disabilities are more vulnerable in times of crisis and
- 92% estimate that these persons are not properly taken into account in humanitarian response. Real efforts are being made to fill this gap as 63% of humanitarian actors state they have developed specific projects or policies
- Finally, only 30% to 45% of the services they provide are reported as accessible to persons with disabilities.

Upcoming Events

Humanitarian Response Intensive Course (HRIC)

Organisation: **Harvard Humanitarian Initiative**

Location: **United States of America**

Date: **19 to 01 May 2016**

BOOK LAUNCH: '[Humanitarian Ethics: A Guide to the Morality of Aid in War and Disaster](#)'

Hugo Slim – Head of Policy at the ICRC **27 October 2015, 4:30 PM UK,**

<http://www.alnap.org/event/900.aspx>

New articles.

* Authored by Network member(s)



*Eckenwiler L, Hunt M, Ahmad A, Calain P, Dawson A, Goodin R, Messelken D, Rubenstein L, Wildi V. 2015. "Counterterrorism policies and practices: health and values at stake." *Bull World Health Organ* 93: 737-738.

*Hunt MR, Chung R, Durocher E, Henrys JH. 2015 "Haitian and international responders' and decision-makers' perspectives regarding disability and the response to the 2010 Haiti earthquake." *Global Health Action* 08/2015; 8:27969. DOI:10.3402/gha.v8.27969

*Nixon SA, Hunt M. 2015. "Global Health: Where Do Physiotherapy and Rehabilitation Research Fit?" *Physiotherapy Canada* 08/2015; 67(3):217-218. DOI:10.3138/ptc.67.3.GEE (French Version: Nixon SA, Hunt M, "Santé mondiale : Quelle est la place de la recherche en physiothérapie et en réadaptation?" *Physiotherapy Canada*, 08/2015; 67(3):219-220. DOI:10.3138/ptc.67.3.GEF)

*Nouvet E. 2015. "Beyond Doing Good: An Interview with Dr. Kirsten Johnson on the Canadian Disaster and Humanitarian Response Training Program." *BioéthiqueOnline* 2015, 4/24. <http://bioethiqueonline.ca/docs/4/24.pdf>

*Nouvet E, Murphy T, Schwartz S. 2015. "Under pressure to act in a humanitarian emergency (Patient's best interest in a humanitarian emergency)". Royal College of Physicians and Surgeons of Canada. Online Bioethics Curriculum: Cases: Section VIII – Global Health. <http://www.royalcollege.ca/portal/page/portal/rc/resources/bioethics/cases/section8>

References from Editorial, p. 1-2:

¹<http://www.un.org/disabilities/default.asp?id=18>

²IFRC (2007). World disasters report: focus on discrimination. Geneva: International Federation of Red Cross and Red Crescent Societies.

³Bonn Declaration. Disasters are always inclusive. Persons with disabilities in humanitarian emergency situations. Bonn, Germany, 7-8 November 2007. http://www.handicap-international.de/fileadmin/redaktion/pdf/bonn_declaration.pdf

⁴WHO (2013). Guidance note on disability and emergency risk management for health. Geneva: World Health Organization

⁵UN General Assembly. Convention on the rights of persons with disabilities: resolution/adopted by the General Assembly. A/RES/ 61/106. 2007. <http://www.un.org/disabilities/default.asp?id=61>

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¹Beck, U. (2015) Emancipatory Catastrophism: What Does It Mean To Climate Change And Risk Society? *Current Sociology*, 63 (1): 75-88.

²United Nations High Commission for Refugees (UNHCR) (2014). *War's Human Cost*. Geneva: UNHCR

³Berghs, M. (2015) Disability and Displacement In Times Of Conflict: Rethinking Migration, Flows And Boundaries. *Disability and the Global South*, 2 (1). <https://disabilityglobalsouth.files.wordpress.com/2012/06/dgs-02-01-03.pdf>

⁴Berghs, M. (2015) Disabled states and Impaired Citizens in the Global South: Bio, Necro to Impairmetrics. *Minority Reports*, (forthcoming)

⁵Johnson, C., Jones, R., Paasi, A., Amoore, L., Mountz, A., Salter, M., & Rumford, C. (2011). Interventions On Rethinking 'The Border' in Border Studies. *Political Geography*, 30 (2): 61-69.

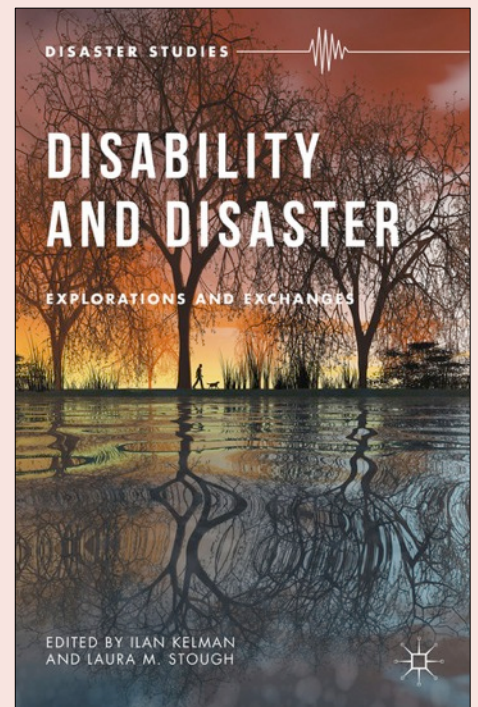
New books.



Disability and Disaster Explorations and Exchanges

Edited by Ilan Kelman and Laura M. Stough
Palgrave Macmillan, 2015.

From the publisher: *Disability and Disaster* adds disaster research to the expanding area of disability studies. This edited collection includes writings by international scholars and first-hand narratives from individuals with disabilities, or knowing people with disabilities, affected by disaster. In this collection, the editors, Laura M. Stough and Ilan Kelman, have embraced the call from the disability community to write "nothing about us without us," while incorporating reflections from scholars studying why certain groups are more vulnerable to disasters than others. In these first-hand narratives, authors with disabilities do not label themselves as "victims" of disaster or of disability. Rather, they portray agency and self-reliance. As such, these narratives present a counter-narrative to the assumed vulnerability and weaknesses of individuals with disabilities.



Gill, Michael, and Cathy J. Schlund-Vials, eds. 2014. **Disability, Human Rights and the Limits of Humanitarianism**. Ashgate Publishing. 280 pp. Hb.: US \$111.25. ISBN-13: 978-1472420916

Koch, Erin. **Blind Spot: How Neoliberalism Infiltrated Global Health**. Salmaan Keshavjee. Oakland: University of California Press, 2014, 240 pp. DOI: 10.1111/maq.12235

Piotukh, Volha. 2015. **Biopolitics, Governmentality and Humanitarianism: 'Caring' for the Population in Afghanistan and Belarus**. Routledge. 178 pp. Hb.: US \$155.00. ISBN-13: 978-0415855457

Slim, Hugo. 2015. **Humanitarian Ethics: A Guide to the Morality of Aid in War and Disaster**, Oxford University Press. 224 pp. Pb: US \$29.95. ISBN-13: 978-0190264833

Street, Alice. 2014. **Biomedicine in an unstable place. Infrastructure and personhood in a Papua New Guinean hospital**. Durham, NC: Duke University Press. 304 pp. Pb.: US\$19.58.

HUMETHNET IS A COMMUNITY OF PRACTICE COMMITTED TO DEVELOPING & USING RESEARCH, EDUCATION, POLICY, AND/OR TOOLS TO ADDRESS ETHICAL CHALLENGES IN HUMANITARIAN HEALTHCARE IN ORDER TO REDUCE PRACTITIONERS' MORAL DISTRESS AND IMPROVE ETHICAL PRACTICE AND DECISION-MAKING AT MULTIPLE LEVELS.

-HumEthNet working statement

ABOUT Reflections

REFLECTIONS is a semi-annual publication written by and geared to a range of actors in the realm of humanitarian healthcare.

The newsletter is available online and in pdf formats. Subscription to the newsletter is free. It is co-edited by *Sonya de Laat* and *Elysée Nouvet* from the hherg at McMaster University.

We welcome submissions in the form of humanitarian healthcare ethics-related events promotion, reviews of books, films, exhibits or events, and recommendations for new readings, viewings, and websites. If you wish to make a submission, offer feedback or suggestions, please write the editors at humethnet@gmail.com.

The Humanitarian Healthcare Ethics Network, HumEthNet, was inaugurated on November 22-24, 2012, in Hamilton, Canada at the Humanitarian Healthcare Ethics (hhe) Forum, hosted by the hhe Research Group with funding from CIHR. Participants are from a variety of disciplinary, organizational, professional, and country backgrounds engaged in the development of realistic applications for ethics in humanitarian healthcare practice. For information on membership contact humethnet@gmail.com.



For more information on the HumEthNet or the hhe Research Group visit:

www.humanitarianhealthethics.net