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Disability and Humanitarianism in Refugee Camps: the case for a travelling supranational disability praxis

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ABSTRACT *There are an estimated 43.3 million forcibly displaced people around the world, many of whom live in refugee or internally displaced camps. These camps are disproportionately congregated in the developing world, making them a prevalent, yet often overlooked landscape in the global South. Among the scores of refugees living in refugee camps is a large number of people with disabilities. This article provides an overview of humanitarian practices and their guiding philosophies and how these address disability issues within the context of refugee camps. Examples of grassroots initiatives related to disability rights and disability inclusion within refugee camp settings are also provided. Using these examples, the paper makes the argument that refugee camps offer fertile grounds for the diffusion of a community-engaged, grassroots disability praxis across the humanitarian field and beyond.*

In a world increasingly blighted by political repression, armed conflict, natural disasters and large-scale infrastructural development, being displaced in search of safety, protection and rights characterises the reality for many people. At the end of 2009 the number of people forcibly displaced from their homes and communities was estimated to be 43.3 million, the highest it has been since the mid-1990s.[1]

Although forced displacement is a global issue, its impact is mostly borne by the Third World. Developing countries host nearly four-fifths of the world's forcibly displaced population.[2] Many displaced people live in refugee or internally displaced camps for variable lengths of time,[3] sometimes spanning generations. Again, these camps are disproportionately congregated in the developing world, making them a prevalent, yet often overlooked landscape in the global South.

The scores of refugee camp inhabitants include large numbers of people with disabilities. Disabled people are estimated to comprise about

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seven per cent to 10 per cent of the world's displaced population.[4] Situations that trigger forced displacement, and subsequent refugee camp conditions, further contribute to the numbers of people with disabilities.[5] At the same time people with disabilities are often excluded within humanitarian programmes and services targeted at refugee camps.[6]

Thus far, disability in the context of refugee camp settings has received scant attention within both development and disability studies. Often located in rural border regions of the Third World, refugee camps have occupied sites that are both geographically and discursively peripheral. This article seeks to draw this neglected landscape out of the hinterlands and into the spotlight by: 1) presenting an overview of humanitarian practices and their guiding philosophies related to addressing disability issues within the context of refugee camps; 2) identifying contemporary and emerging grassroots initiatives targeting disability rights and inclusion within refugee camps; and 3) discussing how refugee camps, despite being segregated enclaves, offer scattered moments for the advancement of a grassroots, community-engaged disability rights praxis within a larger supranational dynamic.

In making the above points, the article draws upon the author's ethnographic research,[7] research from other sources and correspondence with practitioners in the field.

Disability and humanitarianism in refugee camps: an overview

Humanitarian interventions in refugee situations have been widely criticised for ignoring the needs of refugees with disabilities.[8] Disability advocates have pointed out that, despite recognising this gap, humanitarian agencies have been slow to respond. These agencies have tended to view people with disabilities as 'different' from other refugees, contending that disability issues require a special 'expertise' and are therefore outside the realm of their respective mandates.[9] While this characterisation is largely true, there have been recent indications of a growing disability consciousness in the humanitarian field. For example, the summer 2010 issue of the *Forced Migration Review*, a widely read publication in the field, was dedicated to examining the state of the field in response to displaced people with disabilities.

Although long coming, this recent interest in disability has antecedents that can be traced back to the 1980s. In 1981, the office of the United Nations High Commissioner for Refugees (UNHCR), a lead agency in the humanitarian field, was awarded the Nobel Peace Prize and used the prize money to establish a Special Trust Fund for Handicapped Refugees in recognition of the International Year of Disabled Persons commemorated the same year. The Trust Fund was intended for use with qualifying disabled refugees in need of medical treatment not available in their country of refuge. Framed within the medical rehabilitation paradigm, the programme prioritised people with disabilities who were young or heads of their families and who had a favourable prognosis for recovery.[10]

UNHCR's focus on rehabilitation in the 1980s was mirrored in the activities of another emerging player on the humanitarian horizon—Handicap International (HI). Now an acclaimed NGO with an extensive international presence, HI was conceived in 1982 by volunteer French doctors with the primary intention of establishing orthopaedic centres and rehabilitation programmes for Southeast Asian refugees living in refugee camps in Thailand.[11] During the course of ethnographic fieldwork, the author spoke with disabled Cambodian refugees who had lived in Thai refugee camps in the 1980s and who confirmed the presence of rehabilitation programmes in these camps, including physical therapy, orthotic supports and training in vocations such as basket-weaving and electrical assembly.

The following decade, however, witnessed a paradigmatic shift, at least in theory, from a medical/rehabilitative approach to disability to a more holistic approach concerned with disabled refugees' access to resources and services. In 1992 UNHCR issued guidelines for field officers, addressing the provision of assistance to refugees with disabilities. Steeped in the philosophy of Community-Based Rehabilitation (CBR), these guidelines emphasised that assistance for disabled refugees must be 'based on the concept of community level care and incorporated into the overall care and maintenance program [for refugees] ... to achieve equal access of disabled refugees to all societal sectors'.[12] A 1996 revision of these guidelines retained the CBR philosophy and identified a two-pronged humanitarian strategy for addressing disability. This strategy emphasized individual-focused prevention and rehabilitation on one hand, and community-focused awareness and inclusion campaigns on the other. Although these guidelines broadened the focus of humanitarian intervention *vis-à-vis* disabled refugees, they retained a medical/rehabilitation orientation stressing medical screening, prevention and treatment as important strategies. Within these guidelines disability was framed as an exclusively medical issue, modelled after the World Health Organization's (WHO) 1980 publication, International Classification of Impairments, Disabilities, and Handicaps.[13]

Furthermore, there is little evidence that the community-wide inclusion and accessibility advocated in these guidelines made the leap from paper to practice, with the majority of humanitarian workers being reportedly unaware that the guidelines even existed.[14] Field reports from multiple refugee camps indicate that shelters, food and non-food distribution, toileting and bathing facilities, schools, health centres and camp offices continued to be inaccessible to refugees with disabilities. These reports were corroborated by the author's field research with disabled Somali and Cambodian refugees who had lived in refugee camps in Kenya and Thailand, respectively. Despite having inhabited different camps, and nearly 20 years apart, both groups cited similar concerns about lack of accessibility and inclusion within the spatial and programmatic ordering of refugee camps.

However, the Somalis who had lived in refugee camps as recently as 2007 reported recent improvements in the form of more secure shelters for people with disabilities and easier access to food distribution. These provisions were possibly guided by the common humanitarian practice of identifying especially 'vulnerable' individuals in need of special interventions. To assist

humanitarian workers in identifying 'vulnerable' or 'at-risk' individuals, UNHCR released an assessment tool, the Heightened Risk Identification Tool, in 2007.[15] The tool includes different risk indicators under six categories: women and girls, unaccompanied children, older persons, survivors of violence and torture, persons with health needs, and persons with legal or physical protection needs. Disability is included under the health needs category. This tool, and the general approach of categorising individuals and groups as 'vulnerable', has been criticised for essentialising disabled refugees' vulnerability while overlooking their strengths,[16] and for confining a cross-cutting issue such as disability within the narrow framework of health and medical need.[17]

To engender a broader, multisectoral approach to working with disabled refugees, a coalition of NGOs successfully lobbied for an Executive Committee Conclusion on Disability—an expression of consensus between humanitarian actors regarding the principles of international protection of displaced persons with disabilities.[18] This recent initiative, mobilised and adopted in 2010, is notable for two reasons. First, it represents a cross-constituency group of organisational actors (humanitarian service agencies,[19] refugee women's advocacy groups,[20] and international grassroots disability rights organisations[21]), all coalescing around disability rights within the context of humanitarian work. Second, in light of the promise of prior Conclusions on women and children,[22] the Conclusion on disability can potentially drive innovations in the field to address existing gaps.

Disability rights and inclusion in refugee camps: indigenous grassroots efforts

Despite (or perhaps because of) the slow evolution of the institutional humanitarian response to disability issues, refugees with disabilities and their allies have exploited their forced contingency in refugees camps to mobilise around disability rights and inclusion. Some of these mobilisations have been initiated by indigenous actors without any external patronage, while others have been fostered and supported to varying extents by international NGOs or humanitarian workers.

For example, the Somali refugees who participated in the author's research talked about disability conferences and workshops organised in refugee camps in Dadaab, Kenya, by a 'white lady' from an 'American agency'. The conferences were intended as a forum for the camp's disabled inhabitants to share their concerns and collectively articulate their needs. Although initiated by a foreign aid worker, these conferences were seemingly embraced by the local refugees. Somali refugees interviewed by the author reported attending these conferences, with some also contributing to them through *buraanbur* recitals[23]—an indicator that disabled Somalis who attended these meetings were not just receptacles of Western-mediated rhetoric but were also actively engaged in the rhetoric and in making it their own. As one Somali refugee put it, participating in these conferences fostered among disabled refugees the sense that 'we had purpose, we had unity'.[24] Since all the Somali refugees interviewed were subsequently resettled in the US, it is not clear whether

these conferences were sustained. What is clear, however, is that, spurred by the response to this initiative, UNHCR invited HI as an operating partner specifically to improve conditions for people with disabilities in those camps and to mainstream disabled people within camp services and programming.[25]

Similar to the above example, Caritas, an international NGO, has been credited with bringing together 55 Bhutanese mothers of children with disabilities living in refugee camps in Nepal for a month-long training on family planning and care-giving skills. Connections developed during this training endured after its completion, with the women organising their own support groups to address needs beyond the scope of the original training, such as development of a communal savings and credit programme.[26]

Elsewhere in refugee camps, enterprising refugees with disabilities have taken it upon themselves to mobilise resources to fill service gaps overlooked by humanitarian agencies. For example, a landmine survivor in Mae La refugee camp in Thailand founded Care Villa after realising that large numbers of landmine survivors lacked needed services. Care Villa is a facility that offers emotional support, rehabilitation care and vocational training for landmine survivors in the camp with no family support.[27] Further north, along the Thai–Burma border, a Burmese amputee has been running the prosthetics department of a grassroots medical clinic in Mae Sot town. The clinic, which serves Burmese migrant workers and refugees, was founded in 1989 by a Burmese Karen doctor, herself a refugee driven out of the country by the Burmese military regime. The prosthetics department was added to the clinic in 2001 to provide free surgical, post-operative and vocational training for Burmese amputees crossing the border into Thailand.[28] The disabled individuals spearheading these efforts in Mae La and Mae Sot have also collaborated under the aegis of the Karen Handicapped Welfare Association to mobilise international donors in the surreptitious import of prosthetic equipment for landmine survivors living in the mountainous Karen state within Burmese borders. This endeavour is especially noteworthy for drawing international attention to a remote and often-ignored political conflict while directly defying a restrictive agreement between Thai and Burmese authorities prohibiting cross-border activities, including humanitarian aid.[29]

Some disabled refugees have organised themselves to lobby for rights and resources beyond prosthetic rehabilitation. A fitting example here is the Gulu Disabled Person's Union (GDPU), a network of five advocacy groups in one of the worst conflict-affected districts in northern Uganda. GDPU's advocacy efforts date back to 1979 during the violence that erupted after Idi Amin's regime was overthrown, when a group of disabled individuals lobbied the local District Commissioner for more equitable access to humanitarian food distribution programmes. GDPU's political advocacy continues in the aftermath of the most recent violence in Uganda unleashed by the Lord's Resistance Army. The Union's members, many of whom live in internally displaced camps, continue to promote the inclusion of people with disabilities in Uganda's post-conflict reconstruction and peace-building efforts.[30]

Uganda's Gulu district is also the birthplace of another small, yet remarkable endeavour spearheaded by local women with disabilities. The Gulu District Association of Women with Disabilities (GDAWD), an affiliate of GDPU, is an informal group of seven to eight women who have come together to support and educate disabled women and the broader disability community about HIV/AIDS. Speaking publicly about their own HIV status, these women are pioneering the integration of disability rights within HIV/AIDS advocacy and programming at a time when international relief organisations with more influence and bigger budgets have failed to do so.[31]

There are also examples of disability advocacy and networking across gender, ethnic and national divides. In Dzaleka camp in Malawi disabled Congolese, Rwandan, Burundian, Ethiopian and Somali refugees have come together to form an association called *Umoja*, the Swahili word for unity. *Umoja*'s membership includes disabled men and women and parents of disabled children. Members of the organisation used their own labour to build a centre in the camp, and continue to work with humanitarian staff for better access to camp resources for disabled refugees and for the development of respite care and community awareness programmes.[32]

Elsewhere disabled nationals in host countries have reached out to refugee settlers with disabilities. The work of Kaganzi Rutachwamagayo is one example. Kaganzi, a prolific Tanzanian disability activist, was involved in mobilising peer support for disabled survivors of the 1994 Rwandan civil war who had sought shelter in Benaco refugee camp in Tanzania.[33] There are also reports of disabled Iraqis living in refugee settlements in Jordan being invited to join support networks of disabled Jordanians.[34] What makes such outreach efforts remarkable is their occurrence within the context of nationalist discourses that are generally hostile toward refugees.[35]

Efforts toward disability inclusion in refugee camps have also emerged from allied constituencies. For instance, the Karen Women's Organization (KWO), an indigenous organisation run by volunteer women from the Karen ethnic group, teamed up with World Education, an international non-profit organisation, to provide special education and early intervention services in seven Karen refugee camps in Thailand. An important component of KWO's agenda since 2003, these efforts have contributed to the documentation of Karen sign language and the dissemination of Karen Braille.[36] Akin to the cross-constituency initiatives of KWO, the Bhutanese Refugee Women's Forum is another organisation spearheaded by refugee women and actively working towards integrating men and women with disabilities in their capacity-building efforts in camps hosting Bhutanese refugees in Nepal.[37]

Discussion

Information presented in this article suggests that the institutional humanitarian response to disability issues has been both slow in development and inconsistent in application between principle and practice. Aside from the institutional response, however, and despite resource limitations, there have emerged some promising examples of disability advocacy and

organising within refugee settlements. In highlighting these examples, the goal is not to legitimise the poor living conditions and involuntary confinement of stateless persons in these settlements. Rather, it is to suggest that resistance, like oppression, has a spatiality, in which it is mapped and which it seeks to change.[38]

In this sense refugee camps represent a unique 'hybrid' spatiality,[39] one where local articulations of disability encounter and brush against external articulations brought in by international aid agencies. Such encounters, between the local and the external, create new a terrain with its own set of contestations and opportunities. Contestations can arise when disability frameworks and interventions, with operational and theoretical groundings in the industrialised nations of the global North, are imposed upon the local context of refugee camps. The same terrain, however, is replete with opportunities for experimentation with external interventions and for the latter's transformation to suit local needs and contexts.

Among the various initiatives identified in the previous section, the *buraanbur* recitals by disabled Somali refugees at disability conferences organised by a Western aid worker serve as an apt example of embracing an external intervention and infusing it with local flavour. Another good example is that of mothers of disabled children in Nepal, who seized the opportunity provided by an international aid agency to coalesce around the more locally relevant need for communal credit and savings.

Examples cited in the previous section also indicate that grassroots disability advocacy reflects the material reality of the specific locations where it is contested. For instance, disabled activists in Uganda have chosen to focus on HIV/AIDS. Activists living in landmine-infested regions of Southeast Asia have chosen to focus on acquisition of prosthetics. Disability activists in the global North might contend that anything short of advocating equal rights for people with disabilities is not 'activism'. Yet to make this claim would be tantamount to denying global inequalities, where health care and resources taken for granted in some parts of the world need to be fought for in others.

Based on the information presented in this article, one could also make the argument that refugee camps have been sites of innovation in disability rights praxis. For example, GDPU's founding members started lobbying for equal access to humanitarian programmes for people with disabilities in 1979, a time when institutional actors such as UNHCR barely recognised the presence of people with disabilities among refugee populations. Similarly, in kick-starting the integration of disabled people into HIV/AIDS programmes, the GDAWD is far ahead of established NGOs working in the same region.

Finally, the cross-constituency advocacy and organising around disability issues in some refugee situations is seldom seen in developed countries. By connecting across disability, gender, ethnicity and nationality, such initiatives not only disrupt divisive tendencies and authoritative power relations but also defy institutional practices of treating categories of difference, such as gender and disability, in an insular, fixed and isolated manner.[40]

Concluding remarks

Taken together, these disability-related initiatives in refugee camps represent scattered moments for the advancement of a grassroots disability rights praxis within a larger supranational dynamic. Refugee camps straddle nation-state borders and constitute epicentres for global humanitarian networks. Therefore, promising disability-related initiatives within these locales, if brought to the attention of the international humanitarian community, are likely to have far-reaching ripple effects. At UNHCR, for example, the growing disability consciousness and the subsequent imperative to better address the needs of disabled refuges has inspired the agency to look inward and revisit in-house policies for staff with disabilities.[41] Changes within UNHCR are likely to spread across other UN agencies as well as collaborating NGOs within the overall humanitarian network, and from thereon to different parts of the world. To unleash this diffusion of innovations,[42] it is important that the discussion on disability in the context of refugee camps be drawn into the broader disability and development literature. Historically ground-breaking and influential ideas and practices across all fields have travelled from the global North to the global South. Grassroots disability initiatives in refugee camps represent the possibility of a travelling disability praxis where ideas and practices from the global North and South intersect, engage with, and inform each other.

Notes

1 UNHCR, *2010 Global Trends: Refugees, Asylum-seekers, Returnees, Internally Displaced and Stateless Persons*, Geneva: UNHCR, 2010.
2 *Ibid.*
3 Refugee camps host displaced persons who cross international borders; internally displaced camps host displaced persons who remain within national borders. Unless specified, the term 'refugee camps' is generically used throughout the paper to denote both settings.
4 Women's Commission for Refugee Women and Children (WRC), *Disabilities among Refugees and Conflict-affected Populations*, New York: WRC, 2008.
5 LJ Edmonds, 'Mainstreaming community-based rehabilitation in primary health care in Bosnia-Herzegovina', *Disability and Society*, 20(3), 2005, pp 293–309; and P Rockhold & L McDonald, 'The hidden issue in international development aid: health and disability in conflict-affected settings in sub-Saharan Africa', *Journal for Disability and International Development*, 1, 2009, pp 4–11, at: http://www.zbdw.de/projekt01/media/pdf/2009_1_zbdw.pdf, accessed 26 January 2011.
6 M Kett & M van Ommeren, 'Disability, conflict, and emergencies', *Lancet*, 374(9704), 2009, pp 1801–1803.
7 The author conducted an in-depth ethnographic study in 2007–09 involving interviews, focus groups, observations and surveys with seven Somali and eight Cambodian refugees with disabilities resettled in the United States. Another rapid ethnographic study involving interviews and observations with four humanitarian workers and two disability community leaders was conducted in Dzaleka camp, Malawi, in December 2010.
8 Kett & van Ommeren, 'Disability, conflict, and emergencies'; and M Kett & J-F Trani, 'Vulnerability and disability in Darfur', *Forced Migration Review*, 35, 2010, pp 12–14.
9 Kett & van Ommeren, 'Disability, conflict, and emergencies'.
10 WRC, *Disabilities among Refugees and Conflict-affected Populations.*
11 See http://www.handicap-international.us/hi/history/, accessed 26 January 2011.
12 T Degener, 'Disabled persons and human rights: the legal framework', in T Degener & Y Koster-Dreese (eds), *Human Rights and Disabled Persons: Essays and Relevant Human Instruments*, Dordecht: Martinus Nijhoff, 1995, p 32.

13 UNHCR, *Community Service Guidelines on Assisting Disabled Refugees: A Community-based Approach*, Geneva: UNHCR, Community Services Unit, 1996.
14 B Joyce, 'The case for a conclusion', *Forced Migration Review*, 35, 2010, p 44.
15 WRC, *Disabilities among Refugees and Conflict-affected Populations*.
16 M Mirza, 'Resettlement for disabled refugees', *Forced Migration Review*, 35, 2010, pp 30–31.
17 Joyce, 'The case for a conclusion'; and Mirza, 'Resettlement for disabled refugees'.
18 Joyce, 'The case for a conclusion'.
19 A Shivji, 'Disability in displacement', *Forced Migration Review*, 35, 2010, pp 4–7.
20 R Reilly, 'Disabilities among refugees and conflict-affected populations', *Forced Migration Review*, 35, 2010, pp 8–10.
21 C Phillips, S Estey & M Ennis, 'The Convention: on paper and in practice', *Forced Migration Review*, 35, 2010, pp 23–25.
22 Conclusion 107 (Children at Risk) significantly contributed to UNHCR's *Guidelines on Determining the Best Interests of the Child* in 2008 to assist UNHCR and NGOs in implementing child protection procedures. These guidelines have achieved considerable uptake within refugee law discourse. Conclusion 105 (Women and Girls at Risk) led to the 2008 *Handbook on the Protection of Women and Girls*, the establishment of an advocacy and monitoring body for the protection of refugee women, and a target of 10 per cent of women at risk to be resettled in safe third countries. Conclusion 105 has also been drawn upon by UNHCR to prioritise, standardise and systematise sexual and gender-based violence strategies within operations. Joyce, 'The case for a conclusion'; and UNHCR, *A Call to Better Protect Women and Girls: Visibility, Dignity and Livelihoods*, Geneva: UNHCR, Gender Equality Unit, Division of International Protection, 2010.
23 *Buraanbur* is a kind of poetic verse traditionally sung by Somali women.
24 Interview with Fatima (name changed), 4 November 2008.
25 WRC, *Disabilities among Refugees and Conflict-affected Populations*.
26 *Ibid*.
27 *Ibid*.
28 See http://www.maetaoclinic.org/, accessed 26 January 2011.
29 I Mathee, 'Assisting landmine accident survivors in the Thai–Burmese border region', *Journal of Landmine Action*, 9(2), 2006, at: http://maic.jmu.edu/journal/9.2/focus/matthee/matthee.htm, accessed 26 January 2011.
30 Gulu Disabled Persons Union, 'More than a ramp', *Forced Migration Review*, 35, 2010, pp 16–18.
31 M Tataryn, 'Intersection of disability and HIV/AIDS', *Forced Migration Review*, 35, 2010, p 18.
32 Based on interviews with humanitarian workers and disability community leaders in Dzaleka camp, Malawi.
33 Phillips *et al*, 'The Convention'.
34 WRC, *Disabilities among Refugees and Conflict-affected Populations*.
35 For an overview of public discourse and attitudes about Iraqi refugees in Jordan, see PW Fagen, *Iraqi Refugees: Seeking Stability in Syria and Jordan*, Washington, DC: Georgetown University, Institute for the Study of International Migration, 2007, at http://www12.georgetown.edu/sfs/isim/Publications/PatPubs/Iraqi Refugees.pdf, accessed 26 January 2011. For an overview of the refugee situation in Tanzania, see US Committee for Refugees and Immigrants (USCRI). 'Country report: Tanzania', in *World Refugee Survey 2008*, Arlington, VA: USCRI, 2008, at http://www.refugees.org/country reports.aspx?id=2173, accessed 26 January 2011.
36 Karen Women's Organization (KWO), *KWO Annual Report, January 2005–March 2006*, Thailand: KWO, undated, at http://www.karenwomen.org/Reports/Annual Report 2005 COLOUR.pdf, accessed 26 January 2011; and WRC, *Disabilities among Refugees and Conflict-affected Populations*.
37 Bhutanese Refugee Women's Forum, at http://www.brwf.org/Home/success-stories/deaf-mute-barber-trained-by-brwf-inspires-hope-among-disabled-population-in-bhutanese-refugee-community, accessed 26 January 2011.
38 R Kitchen, '"Out of place, knowing one's place": space, power and the exclusion of disabled people', *Disability & Society*, 13(3), 1998, pp 343–356.
39 Here I draw upon post-colonial scholar Homi Bhabha's postulation of 'third spaces', which exist at the points of intersection between indigenous and colonising encounters. These spaces offer sites for resisting colonial hegemony and for articulating new and more egalitarian possibilities and innovations through the emergence of 'hybrid' cultures and practices. H Bhabha, 'Frontlines/borderposts', in A Brammer (ed), *Displacements: Cultural Identities in Question*, Bloomington, IN: Indiana University Press, 1994, pp 269–272.
40 In her analysis of humanitarianism, Hyndman makes a similar argument about UNHCR's treatment of the category of gender as fixed and essentialising. See J Hyndman, *Managing Displacement: Refugees and the Politics of Humanitarianism*, Minneapolis, MN: University of Minnesota Press, 2000, p 82.
41 S Pavey, 'In(house) (dis)ability', *Forced Migration Review*, 35, 2010, pp 42–44.

42 See Rogers' theory on diffusion of innovations. E Rogers, *Diffusion of Innovations*, Glencoe, IL: Free Press, 1962.

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