

2021

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Recommended Citation

Hoagland, Isabelle (2021) "Emerging as a Scholar-Advocate Amid the COVID-19 Pandemic," *International Journal on Responsibility*: Vol. 4: Iss. 1, Article 7.

DOI: <https://doi.org/10.62365/2576-0955.1054>

Available at: <https://commons.lib.jmu.edu/ijr/vol4/iss1/7>

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Emerging as a Scholar-Advocate Amid the COVID-19 Pandemic

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As an undergraduate, I never thought of the countless papers I wrote as having any “real world” significance or impact. After I submitted a paper and got a grade, it was more or less out of sight, out of mind. This year, however, I had an experience that made me realize that academic writing has the power to initiate tangible change. Being two years post-grad, I do not spend a significant amount of time contemplating much of my writing from college, even the two papers that were published during my senior year. This changed when I was contacted regarding a volunteer copyediting opportunity through my profile on the United Nations Volunteers website in the middle of the COVID-19 pandemic. I had the unique chance to directly witness how my writing motivated members of an influential global organization to hold themselves accountable for their ableist framing of disability.

For a Disability and Justice class I took during my final year at James Madison University, I wrote a paper about how the United Nations, specifically the UNHCR (United Nations High Commissioner for Refugees), has framed disability from a medical model perspective throughout the years in various resolutions and policies, resulting in refugees with disabilities not being prioritized for resettlement and remaining stuck in refugee camps with their lives completely on hold. My paper was published in the 2019 Special Issue of the International Journal on Responsibility. It was critical of the UNHCR, and while I acknowledged progress that had been made, I argued that the progress was far too slow and minimal. Throughout college I dedicated my studies, volunteer work and internships towards promoting refugee justice, and UNHCR is an organization I had always admired. For this reason, I was incredibly disappointed in their irresponsible and ignorant position regarding disability.

The UNHCR has historically been quite dismissive of individuals with disabilities, excluding them from important documents and framing them as a burden when they were discussed. For example, a 2004 UNHCR handbook of 500 pages only included one paragraph on refugees with disabilities, stating that “disabled refugees who are well-adjusted to their disability and are functioning at a satisfactory level are generally not to be considered for resettlement” (United Nations High Commissioner for Refugees, 2004, p. 4.11). My paper acknowledged a clear rhetorical shift in how the UNHCR has since progressed language around disability, ending with a 2019 guidebook that calls for universal design in refugee camps and condemns the medical model (United Nations High Commissioner for Refugees, 2019). Despite the advancement, I concluded that the UNHCR still has much room for improvement regarding refugees with disabilities.

When an employee from UNHCR reached out to me this year regarding the volunteer copyediting position, I was a bit perplexed as to why the UNHCR was interested in having me, someone with scarcely any copyediting experience, edit the final version of a training course they were getting ready to publish after two years of hard work. The aim of the course was to train UNHCR employees on how to effectively interview individuals seeking protection and refugee status, to determine the type of protection they were eligible to receive. During our initial introduction meeting, the UNHCR team informed me that they had seen my published paper on the UNHCR and disability on my CV and read it. I was nervous when they brought it up, given my paper's critique of their organization. To my surprise, however, they informed me that they had reached out to me for the position largely because of this very paper.

The project I was editing included an entire section on how to interview refugees with disabilities, and the team quickly admitted to me that disability was not “their area of expertise.” As the training course would be taken by every UNHCR employee conducting protection interviews, they did not want to come across as ill-informed. They felt, given my paper, that I could provide valuable insight regarding the content of the section on disability in addition to the basic copyediting tasks required. Rather than taking offense to the paper, the team recognized that my critique was coming from a place of general admiration and respect for their organization, and my desire for them to be even better for those they serve.

Beginning the project, I was curious where this training course would fit in amongst the various documents, handbooks, and policies that I had written about in my paper in terms of its conceptualization of disability. I was immediately disheartened upon seeing their glossary definition for

disability, which included the phrase: “an individual who cannot function normally within society.” I do not need to explain why such an ableist, medical model definition is problematic. I was frustrated that the language UNHCR was using was a massive movement in the wrong direction, undoing the progress they had been starting to make regarding disability. It was certainly a far cry from the Convention on the Rights of Persons with Disabilities (CRPD) 2006 definition: “Disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others.” While the definition has its shortcomings, it does recognize that disability is a result of environmental factors. Given the UN’s history of excluding disability entirely from conversations and framing it as a medical condition that should ideally be eliminated, the new 2006 CRPD definition was a mark of progress. Yet here we are 15 years later, reversing the improvements that had been made and reverting to the medical model.

As a large and influential global organization, UNHCR has a responsibility to ensure that the language they use is bringing about positive change. Their actions and language set a standard in the global community, and I knew that their new definition of disability was not the standard that should be advanced and presented to the world. So, on my second day of the project, I found myself requesting a team meeting to discuss the issue. The team listened to me give a well-rehearsed speech about the history of the disability rights movement, the medical and social models of disability, the influence that language has, and the UN’s responsibility to improve its rhetoric surrounding disability. I even quoted my previous paper, stating, “When societal rhetoric surrounding disability changes, and the value and worth of individuals with disabilities is recognized and celebrated, it is likely that policies will reflect this” (Hoagland, 2019). They did not respond defensively or skeptically, but were receptive to what I had to say and open to a discussion on how to change their wording.

Together, we spent the remainder of the meeting crafting a definition of disability much more in line with the social model, emphasizing the fact that disability is a result of ableist environmental factors rather than an individual’s perceived ability. It stood out to me that the UNHCR team, comprised of people who are extremely accomplished in the field of refugee protection and well-versed in educating others about various religions, races, ethnicities, sexual orientations, and sensitive political issues, were completely at a loss when it came to the topic of disability. They acted awkward and almost ashamed when disability was mentioned, and at the beginning of our conversation, in a moment of frustration, even suggested deleting it entirely from the course. I believe it is natural as humans to avoid or ignore subjects that make us uncomfortable and potentially highlight our faults, but these are the subjects that must be leaned into and explored for progress to be made. The UNHCR team fortunately was aware of this and continued confronting their uneasiness around disability to improve as an organization.

While I’m contractually unable to discuss the final version of the project, I feel confident in saying that, after the changes we made, this course would be the most in line with the social model of disability out of all the UNHCR documents that I analyzed in my original paper. The team I was working with did exactly what people should do when confronted with a social justice issue that they are uninformed about: they recognized their shortcomings, responded receptively to critique, accepted responsibility, and worked to educate themselves and improve their understanding.

As I reflect back, I realize I would not have been able to take this opportunity had it not been for the pandemic. I found myself without a job and living back at my parents’ house when COVID-19 hit New York City, where I had been working. To make some income safely from home, I found an online job teaching English to students throughout Asia, but the early morning hours I worked left me with a significant amount of free time during the day. My life felt like it was on hold, as was the case for many during this time. As a society we were grappling with the trauma of COVID-19 taking our loved ones so rapidly and in such large numbers, while at the same time, many of us were also forced to move back to readjust the trajectory of our lives. The pandemic took away a number of opportunities for me personally, yet this volunteer copyediting position ended up opening many doors. During such a collectively disastrous time for the world, a time that made many things in life that we used to take for granted inaccessible, many things actually became more accessible as remote work became the norm. It

is important to remember, however, that for those with disabilities, the world we lived in pre-pandemic was never accessible to begin with. I feel lucky to have had the opportunity to do this project remotely and to have had the time in my day to accept a position that would not have been accessible to me before the pandemic.

One of the things that struck me the most about this experience was the fact that a paper I wrote in college, which at the time of writing I never imagined anybody but my professor and myself would ever read, led me to that position of advocating for and helping bring about real change within a prominent organization. While I initially thought that they might take offense to my paper, in reality, they appreciated the critique and acknowledged that it was the push they needed to hold themselves accountable.

Academic writing always felt a bit removed from reality to me in college. No matter how interested I was in a topic, I could not help but feel as though there was little good that could come from writing about issues relating to justice and advocacy, as no real change would come from writing an essay. My experience with the UNHCR turned this feeling completely upside down. I learned that my words have power, and my passion for disability justice and the calls for change that I wrote about were heard. Never in a million years would I have guessed that my paper would be read by staff at UNHCR, but you never know what will happen when you put your words and ideas into the world. I will carry the experience of changing people's mindsets through my writing with me as I begin my graduate education this Fall, and I will never stop writing about and advocating for disability justice.

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