



Bank Street

Occasional Paper Series

Occasional
Paper
Series

Volume 2022

Number 47 *Disabled Lives and Pandemic Lives:
Stories of Human Precarity*

Article 5

April 2022

Is There a Lesson from Comparing the COVID-19 Pandemic to the Experience of Disability? A Response to Carol Rogers-Shaw's "Disabled Lives & Pandemic Lives: Stories of Human Precarity"

Tonette Rocco

Florida International University

Debaro Huyler

Florida International University

Follow this and additional works at: <https://educate.bankstreet.edu/occasional-paper-series>



Part of the [Curriculum and Instruction Commons](#), [Curriculum and Social Inquiry Commons](#), [Educational Assessment, Evaluation, and Research Commons](#), and the [Educational Methods Commons](#)

Recommended Citation

Rocco, T., & Huyler, D. (2022). Is There a Lesson from Comparing the COVID-19 Pandemic to the Experience of Disability? A Response to Carol Rogers-Shaw's "Disabled Lives & Pandemic Lives: Stories of Human Precarity". *Occasional Paper Series*, 2022 (47). DOI: <https://doi.org/10.58295/2375-3668.1442>

This Article is brought to you for free and open access by Educate. It has been accepted for inclusion in Occasional Paper Series by an authorized editor of Educate. For more information, please contact kfreda@bankstreet.edu.

educate

Is There a Lesson from Comparing the COVID-19 Pandemic to the Experience of Disability? A Response to Carol Rogers-Shaw’s “Disabled Lives & Pandemic Lives: Stories of Human Precarity”

Tonette S. Rocco and Debaro Huyler

The COVID-19 pandemic was uncharted territory that sparked fear for many. The pandemic forced us to discover our resilience and devise new coping techniques for life as we were exposed to daily news stories of hospitalizations and deaths. Amid a sea of pandemic stories, a single experience is easily lost. During the pandemic, people dealt with physical and social isolation, uncertainty, and anxiety about the future, economic insecurity, illness-related stigmas, and a lack of access to healthcare and technology.

In “Disabled Lives & Pandemic Lives: Stories of Human Precarity,” Carol Rogers-Shaw narrates several stories that convey the anguish, trauma, loss, and horror experienced by many during the pandemic. Through storytelling, she demonstrates that “the pandemic experiences we shared might provide a foundation to build ... parallels between living with a disability and living in a pandemic.” Even so, Rogers-Shaw cautions us not to get distracted by pandemic-related issues or inspirational stories. Instead, she correctly points out that COVID-19 pandemic experiences mirror the unpleasant aspects of daily life for people with disabilities.

In early 2022, a media discussion rages over whether we should treat the pandemic as an endemic and return to normalcy. The obsession with normalcy reflects the societal construction of disability. This point is exemplified by an evaluator’s surprise and praise in response to Rogers-Shaw telling a group of students with disabilities, “When you are in college you will need to write analytical papers.” Rogers-Shaw’s expectations for the students were identical to those she would have for nondisabled students. However, she points out that in general, we view disability as an abnormality and a deficit. This dominant view of disability ignores lived experiences. While scholars have long opposed the deficit framing of disability, avoiding it has created an insidious dilemma. People with disabilities and their loved ones are cautious about openly communicating their experiences of grief, loss, and trauma to avoid discrimination and reinforcing a deficit-based perspective of disability.

Different disabilities are judged differently (Procknow & Rocco, 2016). For instance, as an ableist society, we sympathize with people with a visible disability and are suspect of those with an invisible cognitive or mental disability. Feelings of both sympathy and suspicion in response to disability are the result of the marginalization of disability as an identity. Tragically, the deficit-based view of disability coexists with the belief that accommodations provide an unfair benefit to the person receiving them (Leef, 2010). Some have gone as far as to argue that an accommodation denies resources to more deserving people and assigns special rights to those with disabilities. The pandemic has created a similar viewpoint; there are those who feel that, like the disability rights

movement, public health initiatives favoring precautions infringe on their rights. As Rogers-Shaw points out, we might be able to see our way past precarity if we view both accommodations and pandemic precautions as tools that might benefit everyone.

This perspective, however, requires embracing creative thinking and solutions that provide another way to consider the skill set and ingenuity of disabled persons. Instead, creative solutions designed by people with disabilities are often viewed with patronizing admiration as courageous efforts to compensate for disability, until nondisabled people also adopt those technologies. Recorded books are a prime example of a creative solution to an accessibility problem. They were devised to provide access to a book's content to someone who has difficulty seeing the words on a page. Recording books, especially textbooks, used to be expensive and time consuming. While there is still work to be done in this area, recording books has become more affordable, and most books, including textbooks, are now available in audio and digital formats.

When I (Tonette, a person without a disability) was in college, I never needed permission to record a class. In fact, I was considered a model student for recording lectures. When my now husband recorded a class, he had to get permission and bring paperwork with him to certify that he had a disability and therefore a right to this accommodation. His instructors responded to him with suspicion and incredulity, and worse: they questioned his intentions. He was never regarded as a model student. Despite these difficulties, he persevered through college graduating with honors. This is an example of how ingrained the perspective is that people with disabilities are less than people without disabilities, and that they are not entitled to what people without disabilities have and take for granted.

In some communities, disability is not regarded as a lack of ability or a deficit. A person who lacks a limb or processes information differently is simply believed to have diverse skills. These communities, however, are rapidly disappearing. Martha's Vineyard is a fantastic example of this. In the past, when the island was essentially isolated from the mainland, the substantial deaf population was simply a part of the community, and everyone on the island learned to communicate using sign language (Conan, 2006), diminishing social barriers. Shamanism provides another example of this. As Stone (2018) explains, in shamanism, there is "no assumption of a static recognizable human body" (p. 2). A static human body is one we might call able-bodied, normal, or temporarily able-bodied (Zola, 1993). Instead, in shamanism, bodies and minds, disease and disability are seen through a lens of spirituality that does not diminish the person. The deficit view is a modern westernized notion that puts people into boxes based on visible identity characteristics (Mizzi & Rocco, 2013). Rogers-Shaw rightly emphasizes that we must be wary of Western societies' deficit view of disability because it ultimately builds narratives that suggest that life is a battle between the nondisabled and the disabled—the disabled fight to have their lives valued while the nondisabled assume their lives are the only lives worth living.

The notion that people with disabilities or chronic illness are expendable because their lives are less worthy existed before the pandemic. While Americans widely expressed

remorse about the high number of deaths at nursing homes and of medically fragile people, those who died were often considered simply unfortunate. The division between “them” (those who are susceptible to the virus) and “us” (those who need to protect them) persists. Arguably, for people without disabilities living through the pandemic, the lesson of the precarity of life has not been learned. A vocal group—hopefully a minority—even considers that getting a vaccine or wearing a mask to protect others, even those in one’s own family, is an infringement of individual rights.

Disability scholars and social justice advocates continue to bemoan the inadequate language regarding disability, struggling to find new ways to articulate the strength and courage of a person with a disability who overcomes a multitude of obstacles—a way of framing disability that is just as inadequate as the deficit model. We talk about inclusion, accommodation, adaptation, and the social construction of disability—yet change little in how we think, speak, or act. When an action is considered an accommodation, people without a disability often regard it as an affront, a special advantage, unearned and undeserved (Rocco, 2010). But the same action, when used to benefit someone without a disability, is taken for granted and accepted nonjudgmentally. When a child is born with a disability, parents and other family members grieve before celebrating the child (Rose, 2021). Meanwhile, strangers offer sympathy. We do not see the child as having a future full of possibilities.

Unfortunately, the framing of disability is surrounded by myths, legends, and horror stories about the abilities, aptitudes, and preferences of people who have a disability. The worth of a person should not be judged in terms of how much sympathy we think they deserve. Rogers-Shaw makes a point that we should not think in terms of disability, but in terms of differing abilities. We need to make a conscious choice to change the narrative. We need to see creative solutions and problem-solving as just that, regardless of the label attributed to the person who devised the solution. We need to continue moving our society forward so that it becomes one where everyone can feel they belong and are not separated from others because of differences.

Is there a lesson to be learned from comparing the pandemic to the experience of disability? If we accept the fact that life is precarious and that we all have limitations, control is a myth and our collective narrative may be the key takeaways. After the World Health Organization declared a global pandemic on March 11, 2020, many individuals felt and experienced a loss of control. People with disabilities, like those who tell privileged stories about pivoting, sustaining, and surviving during the pandemic, live imaginatively and persist in the face of obstacles. Our common awareness of reality and our empathy for those with a wide range of abilities influence how we construct that narrative.

REFERENCES

- Conan, N. (Host). (2006, October 12). Deaf culture on Martha's Vineyard [Radio episode]. In *Talk of the nation*. NPR. npr.org/2006/10/12/6254177/deaf-culture-on-marthas-vineyard
- Leef, G. (2010, March 30). *Helping hand or unfair advantage?* The James G. Martin Center for Academic Renewal. jamesgmartin.center/2010/03/helping-hand-or-unfair-advantage/
- Mizzi, R. & Rocco, T. S. (Sept. 2013). Deconstructing dominance: Towards a reconceptualization of the relationship between identity, globalization and learning at work. *Human Resource Development Review*, 12 (3) 364-382. DOI 10.1177/1534484313477410
- Procknow, G. & Rocco, T. S. (2016). The unheard, unseen, and often forgotten: An examination of disability in the human resource development literature. *Human Resource Development Review*, 15(4), 379-403. doi.org/10.1177/1534484316671194
- Rocco, T. S. (2010). The invisible people: Disability, diversity, and issues of power in adult education. *International Journal of Disability Studies* 4(1 & 2), 144-153.
- Rose, C. (2021). Narrative Experiences of Fathers of Children with Down syndrome. (Educational Studies Dissertations, Publication No. 178) [Doctoral dissertation, Lesley University]. digitalcommons.lesley.edu/education_dissertations/178
- Stone, R. R. (2018, Spring). Empowered, not disabled: An ancient shaman effigy vessel at the Carlos Museum. *The Journal of Humanities in Rehabilitation*, 1-9. jhrehab.org/2018/04/30/empowered-not-disabled-an-ancient-shaman-effigy-vessel-at-the-carlos-museum/
- Zola, I. K. (1993). Self, identity and the naming question: Reflections on the language of disability. *Social Science & Medicine*, 36(2), 167-173.

ABOUT THE AUTHORS



Tonette S. Rocco is a professor in adult education and human resource development at Florida International University in Miami, Florida. She co-edited the *2020 Handbook of Adult and Continuing Education* (Rocco, Smith, Mizzi, Merriweather & Hawley, 2020), and the *Handbook of HRD* (Chalofsky, Rocco, and Morris 2014). She is editor-in-chief of *New Horizons in Adult Education and Human Resource Development*. Her research interests include disability disclosure and equity.



Debaro Huyler is director of administration in academic and student affairs at Florida International University (FIU). He is also an instructor and doctoral candidate in FIU's College of Arts, Sciences, and Education. His scholarly interests include marginalization, generational studies, qualitative research methods, social entrepreneurship, and crisis management.