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Commentary

Remnants of Community: What I Learned in the First Year of the Pandemic

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Abstract

This commentary reflects briefly on 10 of the many lessons that defined the Covid-19 pandemic. These reflections are taken from one disabled person's experience but resonate with many. As such they give a flavour of the thematic issue as a whole, while offering a highly personal contribution to the publication project.

Keywords

ableism; activism; coronavirus; disability; silencing; social change

Issue

This commentary is part of the issue "Disability and Social Inclusion: Lessons From the Pandemic" edited by Owen Barden (Liverpool Hope University), Laura Waite (Liverpool Hope University), Erin Pritchard (Liverpool Hope University), and Ana Bê (Liverpool Hope University).

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Disability futurity is a concept that, in 2018, I adopted for a project in the Centre for Culture and Disability Studies at Liverpool Hope University. Many internal and external colleagues were ultimately involved (e.g., Murray, 2022; Penketh, 2022) and the research followed various directions in Canada and the UK (Patterson, 2022; Worthington, 2022). My starting point was an extrapolation from epistemology gained from disability, elsewhere called *cripistemology* (Johnson & McRuer, 2014), as a knowledge base for a future in which increased life expectancy would bring about widespread dependence on accessible technology and a true appreciation of interdependency. This prediction seemed a bit far-fetched, as noted by some colleagues, and in all honesty I was thinking decades down the line. Conversely, to explore my position I harked back to a cultural product of 1957, Samuel Beckett's *Endgame*, which reduced the final phase of humanity to four disabled people whose very existence relied on what remained of community (Beckett, 1957/1964; Bolt, 2021; Davidson, 2007; Quayson, 2007). These Beckettian ponderings acquired pertinence when in March of 2020 I found myself, a lone disabled figure, navigating the desolate landscape of the usually lively Liverpool suburb in which I had lived and worked for more than a decade. Any speculation I had made about disability futurity was consumed in that primal pandemic moment from which I could only learn.

The first lesson I learned was that I was part of a high-risk group. Because I have an autoimmune disease called psoriatic arthritis, I take a disease-modifying anti-rheumatic drug, Methotrexate, which works by suppressing my rogue immune system (Bolt, 2021). Panic led me to infer that my chronic disease might be preferable to the treatment in the fearful context defined by the coronavirus. I figured I might be better off bearing the full, life-changing force of arthritis (Felstiner, 2005), rather than rendering myself prone to the life-threatening virus Covid-19. My inference was far from original, as I realised when I rang the rheumatology nurses to hear an answer-machine message about being inundated with similar enquiries. The pre-recorded advice was to keep taking the tablets and "follow government guidelines." This predicament worsened day by day with news of more cases and more deaths among which I could not help noticing a proliferation of references to the high-risk group that embodied the very reason for lockdown.

The second lesson was that eating out was not a fool-proof means of sustenance. I have an eye disease called retinitis pigmentosa that has long since progressed to the point of sightlessness, which combines with my psoriatic arthritis to complicate the preparation of all but the most basic of meals. I had addressed this situation by making my way to a local eatery each day. In lockdown, however, I could only lament reliance on these short but

regular visits for good food, drink, and exercise, not to mention community beyond work.

The third lesson was that even huge supermarket chains could not necessarily provide timely supplies. Given that, apart from a fifteen-minute walk each morning, I was self-isolating, I required a shopping delivery each week. However, it was thanks only to my daughter's diligence, checking the websites throughout the day and into the night, that I secured a delivery slot every third week. I contacted one famously high-end supermarket several times to explain that even before the pandemic I relied on deliveries for basic household items; alas, neither my manifest desperation nor years of custom carried any weight at all.

The fourth lesson pertained to unexpected sources of support in the local community. One restaurant helped me by setting up a tab, accepting orders via text message, and agreeing to collect and deliver my prescription each month; another, in between lockdowns, allowed me to eat outside set hours and settle the bill retrospectively. Given that work had taken me away from family and friends more than a decade earlier, and the university around which I had structured my life was all but deserted, it is no exaggeration to assert that a few people in the locality constituted a lifeline.

The fifth lesson was that years of extended time on campus had resulted in a far too basic workstation at home. I found myself working on a decade-old laptop with a poor internet connection, which meant I had no access to Zoom or anything similar. As such, during the first lockdown, in order to join meetings I had to ask a helpful colleague to call me on the telephone, meaning I could just about listen in and be heard. No stranger to access issues, I felt rather outside some discussions but was nonetheless glad of this substandard communication.

The sixth lesson was about the extent to which a visual perspective was taken for granted (Jay, 1993). Shielding letters and other medical correspondence aside, I was at a loss when my trusty laptop broke down and was deemed irreparable, which left me with no means of writing or reading. My institution loaned me a replacement, which was gratefully received but meant I had to learn how to use new versions of all the software, ranging from the operating system and screen-reader to Word, Outlook, Chrome, and Zoom. This would have been difficult enough with sighted assistance but on my own it was frustrating to the extreme. Nevertheless, on more than one occasion I was saved by a kind colleague who made the route to my house part of her *daily exercise allowance* and stood outside my window just to look in and tell me what was on my screen. This being so, in subsequent lockdowns it was necessary for me to meet and work face-to-face with my academic support worker, in what became known as a *support bubble*.

The seventh lesson was that some educators deemed it impossible to teach students without seeing their faces. This ocularnormative assertion was made by tutors who encountered difficulties when giving sessions via Zoom.

The issue was that many if not most students took to switching off their cameras for the duration of taught sessions. I discouraged this practice in my own classes, well aware that visual cues and body language were helpful to many people (Barthes, 1992). More concerning were the pedagogical implications for educators who teach without seeing the faces of students as standard (Michalko, 2001). Had the assertions of impossibility been followed by requests for experiential knowledge, there could have been productive connections; in the absence of such discourse, the normative divide differentiated and distanced my understandings from those of others.

The eighth lesson related to the fact that the deserted pavements soon became cluttered with e-scooters, as a result of a rental scheme endorsed by the City Council. The pleasure principle was not lost on me but the normative positivisms translated into non-normative negativisms. Where the main obstacles once were badly parked cars and unkempt trees, I now needed to beware of more random tests of patience. The e-scooters seemed to take many forms, depending on how they were parked, and could turn up on just about any pavement. More than being an obvious hazard, for a long-cane user they proved disorientating when having to be stepped over or walked around. Although I never forget that disabled people's knowledge tends to be dismissed as "complaining" (Wendell, 1989, p. 104), I did wonder what would happen if comparable obstacles became a feature on the roads. I knew for sure that, for the foreseeable future, I would need to walk at a markedly slower pace to avoid sustaining serious injury.

The ninth lesson pertained to haptic perception. Having recently started to use the long-cane for mobility, after more than three decades of guide dogs, I was becoming increasingly aware that the human sense of touch was indeed underrated (Classen, 2005). After all, I was learning fine details about the local environment that had previously passed me by. The trouble was that in pandemic times all contact had become problematic. For instance, a banister that once reduced the hazard of steps or stairs was now a hazard in itself. This fear of contagion extended to people, manifest in social distancing, which translated into anxieties if not guidelines about a person who perceives by other than visual means taking someone's arm when walking somewhere unfamiliar or busy.

The tenth lesson was that, even though its spectre had lurked at the back of my mind since childhood, the death of a parent is not something for which anyone can prepare. My father had been having varied and multiple cancer treatments for a few years and so was deemed clinically extremely vulnerable. Because we were both in high-risk groups, I did not spend much time face-to-face with him even between the lockdowns of 2020 and 2021. We had our final conversation via telephone, which my brother made possible by ringing me from the hospital. Selfless and understated to the end, my father tried to put my mind at rest by saying he was okay. It seemed

perplexing as much as upsetting that I was not there in person and this unique mix of emotions persisted when he died a couple of days later. Despite the number of times I had rehearsed it in the dreadful corners of my mind, the bizarre reality was completely unexpected, for I donned my suit and attended my father's funeral via the laptop in my living room. Instead of being just fifty miles away with my mother, brother, daughter, and the rest of the tiny gathering allowed at the crematorium, I was joined by my academic support worker of only six months, who silently and sensitively stood to one side but made and maintained my online connection with the funeral service.

Based on 12 months, from March 2020 to February 2021, these lessons from the pandemic are indicative of dozens more; they are profoundly personal but likely to resonate with disabled people lucky enough to have lived to tell the tale. The lessons have been hard learned by a deflated if not defeated professor of disability studies who, just a few years ago, was enthused about the idea of a great tomorrow in which disabled people would share knowledge and experience as a pivotal means of progressing society. Granted, in the first lockdown, I noticed signs that predictions of such non-normative positivisms were not just rhetorical, as disability was indeed recognised as a knowledge base (Bolt, 2021). However, the sheer violence of pandemic categorisation ultimately emphasised the normative social order and deepened the normative divide. Deaths were announced in daily if not hourly news reports with qualifying references to *underlying conditions*, from which most people drew a huge sense of relief. Moreover, the future to which we were all meant to look was the *new normal*, something very different from my non-normative imaginings of disability futurity. What my ten lessons do demonstrate, though, is that in troubled times even remnants of community are vital.

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About the Author



David Bolt is personal chair in disability studies and interdisciplinarity at Liverpool Hope University, where he is also director of the Centre for Culture and Disability Studies and the disability studies MA programme. He is editor in chief of the *Journal of Literary and Cultural Disability Studies*, the book series editor of *Autocritical Disability Studies*, and joint book series editor of *Literary Disability Studies*.

Conflict of Interests

The author declares no conflict of interests.

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