Working *Crip Time*: Exploring the Relationship between Episodic Disability and Work In and After the COVID-19 Pandemic

By Odelia Bay[*]

In my research, I think a lot about episodic disability and work. I come to this field of study as a person who is episodically disabled. I have relapse and remitting multiple sclerosis. In some ways it is the quintessential episodic disability. I'm also a lawyer.

Our jobs define us. Employment is integral to our economic well-being and forms the foundation for our social citizenship. Work is often central to our identity; it allows us to form and fulfill our hopes and dreams; and it provides us with a way to connect with and contribute to our communities.[1]

Nearly a quarter of adult Canadians report having at least one disability.[2] This segment of the population faces higher rates of unemployment and poverty in comparison to their non-disabled counterparts. According to the 2017 Canadian Survey on Disability, nearly 60 per cent of disabled, working-age adults are employed as opposed to 80 per cent of non-disabled adults.[3]

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[*] LL.M. (Columbia Law School), J.D. (University of Ottawa), B.Journ (Ryerson University). PhD student at Osgoode Hall Law School, York University; recipient, SSHRC Doctoral Scholarship to Honour Nelson Mandela. Please note, sections of this are based on my forthcoming chapter in *Law & Disability in Canada: Cases & Materials* (Toronto: LexisNexis, 2021).
This is a draft and not for circulation without permission of the author. Please contact Odelia Bay at odeliabay@osgooode.yorku.ca.

[1] Vicki Schultz, "Life's Work" (2000) 100 Colum. L. Rev. 1881, at 1886-1892.

[2] Stuart Morris, Gail Fawcett, Laurent Brisebois & Jeffrey Hughes, *A demographic, employment and income profile of Canadians with disabilities aged 15 years and over, 2017* (Statistics Canada, 2018) (Catalogue no. 89-654-X2018002), online: https://www150.statcan.gc.ca/n1/pub/89-654-x/89-654-x2018002-eng.htm (22 per cent of people age 15 and older; increasing with age).

[3] *Ibid*. (59% of those with disabilities ages 25-64. But the number changes in accordance with degree of disability; 76% with mild disabilities but only 31% of those with severe disabilities.) In this chapter, I use identity-first and person-first language interchangeably. I also recognize that identity-first terminology is preferred within Disability Studies scholarship.

Likewise, the poverty rate for this same cohort of disabled adults is between 14 and 28 per cent, depending on degree of disability.[4] For non-disabled adults, that number drops to 10 per cent.[5]

Episodic disability refers to a sub-category of disability. In overarching terms, episodic disabilities are long-term conditions with fluctuating and unpredictable periods and degrees of wellness and disability that impact aspects of daily life including work.[6] More than 80 per cent of adult Canadians who report a disability may be classified as having an episodic disability.[7] Of these people, more than three quarters of those who work say their disability impacts their ability to do their job.[8]

Today, I'm going to talk briefly about how episodic disability, and related self-care needs, challenge our normative experiences of time with respect to work, but also create opportunity for change. As part of that, and in the time of COVID-19 in which we find ourselves, it is also important to understand the relationship between *crip time* and *pandemic time*.

Self-Care

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[4] Stuart Morris, Gail Fawcett, Laurent Brisebois & Jeffrey Hughes, *A demographic, employment and income profile of Canadians with disabilities aged 15 years and over, 2017* (Statistics Canada, 2018) (Catalogue no. 89-654-X2018002), online: https://www150.statcan.gc.ca/n1/pub/89-654-x/89-654-x2018002-eng.htm.

[5] Stuart Morris, Gail Fawcett, Laurent Brisebois & Jeffrey Hughes, *A demographic, employment and income profile of Canadians with disabilities aged 15 years and over, 2017* (Statistics Canada, 2018) (Catalogue no. 89-654-X2018002), online: https://www150.statcan.gc.ca/n1/pub/89-654-x/89-654-x2018002-eng.htm. For a discussion on income security and people with disabilities, please see Chapter 6 in this volume.

[6] Much of this definition is based on two sources: House of Commons, *Taking Action: Improving the Lives of Canadians Living with Episodic Disabilities, Report of the Standing Committee on Human Resources, Skills and Social Development and the Status of Persons with Disabilities* (March 2019) (Chair: Bryan May) at 7; and, my work with the Social Sciences and Humanities Research Council (SSHRC) Insight Grant project "InVisibility to Inclusion: Developing and Evaluating Policies and Practices to Facilitate the Inclusion of Workers with Episodic Disabilities in Ontario Workplaces", online, https://www.invisibility2inclusion.ca/.

[7] Adele Furrie *et al*, "Episodic Disabilities in Canada" (Ottawa: Adele Furrie Consulting Inc, 2016) online: http://www.adelefurrie.ca/PDF/episodic_disabilities_in_canada_-_october_4_-_final.pdf (82.4 per cent at 8).

[8] Furrie, Adele. "People with Episodic Health Conditions Speak About…", Final Report for Employment and Social Development Canada (Ottawa: Adele Furrie Consulting Inc, 2017), online: http://www.adelefurrie.ca/PDF/People_with_episodic_health_conditions_speak_out_about.pdf ("Of the remaining 712 respondents [who remain in the workforce], 77% said that their health condition(s) had an impact on their ability to participate in paid work or in a business." At 22).

I think about episodic disability and self-care as care work because of the brilliant feminist scholar, Susan Wendell and her work exploring ideas of what she termed the "healthy disabled" and the "unhealthy disabled."[9] And I also think about self-care, not as a neo-liberal and individualistic practice, but as an integral part of community care.

Audre Lorde wrote, "Caring for myself is not self-indulgence, it is self-preservation, and that is an act of political warfare."[10] Lorde writes this as a woman with intimate knowledge of what it means to be a person with an episodic disability due to chronic illness. Self-care becomes a political act, particularly in the context of employment, when time, energy, and most of all labour power is diverted from productivity to look after one's own well-being.

Although it is largely an individual activity, self-care is something that can be seen to be a social good in much the same way as we value care for others.[11] Links can be made to Michel Foucault's conception of care for the self, not as "a kind of self-love, a kind of egoism or individual interest in contradiction to the care one must show others or the necessary sacrifice of the self," but rather as a practice of self-awareness and self- improvement that contributes to one's own ability to participate as part of a collective.[12] All of this takes time.

Crip Time

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[9] Susan Wendell, "Unhealthy Disabled: Treading Chronic Illnesses as Disabilities" (Fall 2001) 16:4 Hypatia 17.

[10] Lorde, *supra* note 1 at 131.

[11] Odelia R Bay, "Battling the Warrior-Litigator: An Exploration of Chronic Illness and Employment Discrimination Paradigms" in Ben Isitt & Ravi Malhotra, eds, *Disabling Barriers: Social Movements, Disability History, and the Law* (Vancouver: UBC Press, 2017) 125.

[12] Raúl Fornet-Betancourt, Helmut Becker & Alfredo Gomez-Müller, "The Ethic of Care for the Self as a Practice of Freedom: An Interview with Michel Foucault on January 20, 1984" (1997) 12 Philosophy & Social Criticism 112 at 115-16 [translated by JD Gauthier].

Crip time is an idea that comes out of disability (i.e. crip) studies and culture. Irving Kenneth Zola explains that the use of the word "crip" is a political reclamation of disability identity.[13] Crip time specifically refers to a reclaiming of the ways in which time, a measure that often appears neutral on its face, is differently experienced and conceived through a disabled lens as opposed to dominant temporalities.

Elizabeth Freeman is a cultural and queer theorist who has done a lot of thinking and writing about normalcy and time. She offers us two related ways of thinking about how norms around time are constructed. The first, is the concept of temporal mechanisms, which she then builds on through the theory of chrononormativity.[14] Freeman uses the phrase "temporal mechanisms" to refer to the social and political exercises of time that shape and determine relational norms.[15] Time is used to, "[shape] the contours of a meaningful life by registering some events… and refusing to record others."[16] She explains that "time binds" us through acceptable rhythms and rituals thus determining our connections to family, the state, and work.[17]

Temporal mechanisms become inscribed in power dynamics through chrononormativity, which Freeman defines as "the use of time to organize individual human bodies toward maximum productivity. … Schedules, calendars, time zones, and even wristwatches inculcate… forms of

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[13] Irving Kenneth Zola, "The Language of Disability: Problems of politics and Practice" (1988) Australian Disability Review, online: Disability History Museum <http://www.disabilitymuseum.org/dhm/lib/detail.html?id=813&page=all>

[14] Elizabeth Freeman, "Time Binds, or, Erotohistoriography" (2005) 23:3-4 Social Text 57; Elizabeth Freeman, *Time Binds: Queer Temporalities, Queer Histories* (Durham, NC: Duke University Press, 2010).

[15] Elizabeth Freeman, "Time Binds, or, Erotohistoriography" (2005) 23:3-4 Social Text 57; Elizabeth Freeman, *Time Binds: Queer Temporalities, Queer Histories* (Durham, NC: Duke University Press, 2010) at 57. See also Emily Grabham, "The Strange Temporalities of Work-life Balance Law" (2014) 4:1 feminists@law 1 at 2, citing Freeman.

[16] Elizabeth Freeman, "Time Binds, or, Erotohistoriography" (2005) 23:3-4 Social Text 57; Elizabeth Freeman, *Time Binds: Queer Temporalities, Queer Histories* (Durham, NC: Duke University Press, 2010) at 58.

[17] Elizabeth Freeman, "Time Binds, or, Erotohistoriography" (2005) 23:3-4 Social Text 57; Elizabeth Freeman, *Time Binds: Queer Temporalities, Queer Histories* (Durham, NC: Duke University Press, 2010) at 61.

temporal experience that seem natural to those they privilege."[18] We are taught to view these rhythms and rituals as neutral and yet they are weighted measures of productivity and citizenship.[19] In the context of work, they inform when we are expected to start our working lives and end them; the structure of our workday and workweek; issues of pay and benefits; and a number of employment standards.

While everyone's experience of disability is different—adding to the unique and often challenging nature of disability as a protected ground under human rights law—many of the impairments or functional limitations experienced by people with episodic disabilities are related to pain or fatigue.[20] Susan Wendell explains how the fatigue associated with many chronic conditions is very different from the ordinary tiredness many people experience at the end of a long, busy day. She writes:

> [I]t is more debilitating, it lasts longer, and it is less predictable. Every activity, including thinking, watching, listening, speaking, and eating, requires energy. It is possible to be too fatigued to do any of these. … A good night's sleep rarely cures the profound fatigue of illness; it may last for days or weeks with no apparent improvement, or it may fluctuate, allowing some activity punctuated by periods of total exhaustion.[21]

This overwhelming sense of fatigue and the need to ration energy as if it is a limited resource is commonly referred to as "spoon theory."[22]

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[18] Elizabeth Freeman, *Time Binds: Queer Temporalities, Queer Histories* (Durham, NC: Duke University Press, 2010) at 3.

[19] See also, Elizabeth F. Cohen, *The Political Value of Time: Citizenship, Duration, and Democratic Justice* (Cambridge: Cambridge University Press, 2018).

[20] Susan Wendell, "Unhealthy Disabled: Treading Chronic Illnesses as Disabilities" (Fall 2001) 16:4 Hypatia 17 at 24.

[21] Susan Wendell, "Unhealthy Disabled: Treading Chronic Illnesses as Disabilities" (Fall 2001) 16:4 Hypatia 17 at 24-25.

[22] Christine Miserandino, "The Spoon Theory", online: But You Don't Look Sick? <http://www.butyoudontlooksick.com/wpress/articles/written-by-christine/the-spoon-theory/>.

The experience of disability is temporal (time-sensed) as well as corporeal (body-sensed). It seems impossible to describe episodic disability without talking about time. The very word "episodic" means something that is "limited in duration" or "occurring, appearing, or changing at usually irregular intervals."[23] To experience episodic disability is often to experience time that is not only slowed, but irregular, unpredictable, and sometimes cyclical. There is an ebb and flow; space for both anticipation and dread. Time is tied up in impairment, ability, and affect.

On one level, crip time can perhaps be understood as stretched, elongated, or shuffled time. It is the extra time needed to do things as a result of either impairment or assistive measures.[24] For example, it is the time it takes to schedule transportation far in advance of a meeting; sharing the route with others who get on and off at their own pace; detouring to find bathrooms or avoid stairs; looking for barrier-free pick-up or drop-off locations; or being early or late on arrival. It is sometimes the naps in between reading or writing paragraphs, like this one.

Ellen Samuels writes about crip time as time travel:

> Disability and illness have the power to extract us from linear, progressive time with its normative life stages and cast us into a wormhole of backward and forward acceleration, jerky stops and starts, tedious intervals and abrupt endings. Some of us contend with the impairments of old age while still young; some of us are treated like children no matter how old we get.[25]

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[23] *Merriam-Webster's Collegiate Dictionary*, 10th ed. (Springfield, MA: Merriam-Webster, 1998) *sub verbo* "episodic".

[24] Alison Kafer, *Feminist Queer, Crip* (Bloomingdale, Ind: Indiana University Press, 2013) at 26.

[25] Ellen Samuels, "Six Ways of Looking at Crip Time" (2017) 37 Disability Studies Quarterly online: https://dsq-sds.org/article/view/5824/4684.

Careers start, end, or pause at unexpected moments. Disability impacts how others perceive relevant experience, daily commitment to work ethic, or earned promotions; all potential cracks in chrononormativity.

There are also positive aspects to this slowing or reordering of time. While some activities may take longer, space is made for others. Petra Kuppers sees crip time as a form of sanctuary. As she puts it, "moments out of time, out of productive, forward-leaning time," provide opportunities for creativity, contemplation and "disability culture politics."[26]

Crip time is about atypical experiences of the way time flows and expectations related to the passage of time. It is a recognition of the need for flexibility in how time is experienced and even a shifting of temporality as it interacts with others. Kafer has a lovely phrasing for this experiential relationship to time and references the ways in which it can be transformative. She writes:

> Crip time is flex time not just expanded but exploded; it requires reimagining our notions of what can and should happen in time, or recognizing how expectations of "how long things take" are based on very particular minds and bodies. *We can then understand the flexibility of crip time as being not only an accommodation to those who need "more" time but also, and perhaps especially, a challenge to normative and normalizing expectations of pace and scheduling*. Rather than bend disabled bodies and minds to meet the clock, crip time bends the clock to meet disabled bodies and minds.[27]

I love that notions of crip bodies and minds bending normative notions and experiences of time. It's a kind of reciprocity and care in its own right.

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[26] Petra Kuppers, "Crip Time", *Tikkun Magazine* 29:4 (20 October 2014) 29 at 29.

[27] Alison Kafer, *Feminist Queer, Crip* (Bloomingdale, Ind: Indiana University Press, 2013) at 27 [emphasis added].

In and After a Time of Pandemic

I wrote nearly all of this from my bedroom, approximately one year into the pandemic. This time has been extraordinarily transformative. We have restructured our lives to prevent and reduce incidents of illness, disability, and even death. And while we have been motivated by our collective best interests, many of the changes have created more inclusive and accessible working conditions for disabled workers.

The pandemic has changed when, where, and how we work. Many people now work remotely from home, Zooming into video conference calls for meetings with co-workers. Many have adjusted their work schedules to account for the care needs of family members or to accommodate new circadian rhythms that no longer seem to adhere to a regular workday or standard calendar. These changes in how we experience and relate to time also impacts front-line and essential workers who must work on-site. Perhaps their shifts have been altered. Their travel time may have been extended or simply experienced differently with new-found anxiety about safety or contingency plans for bathroom access en route. They have had to learn how to build in extra time to put on personal protective equipment or clean and disinfect.

Collectively, we are all managing time differently. Without routines, our sense of time is muddled. For some, time is felt as a loss; for others, a confusing loop.

In her recent writing, Freemen, mentioned above, writes that pandemic time is "'crip time' for the masses."[28] Disabled or not, we are all learning about isolation, delayed gratification, the

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[28] Elizabeth Freeman, "Time" (9 March 2021) Issues in Science and Technology online: https://issues.org/time-postpandemic/.

blurring of work-life and home-life, and evolving understandings of mortality. But is it really crip time?

Certainly, some of the experiences are eerily similar. But in other ways that are not at all alike. The disability community has expressed frustration over the fact that accessible and flexible work—and even social time—were not made available to them before the pandemic and are now commonplace for the able majority. Many disabled people have raised concerns about returning to a less accessible world once COVID is behind us.

The idea of returning to normal—or a new normal—makes pandemic time very different from crip time. Once COVID is behind us, some folks will be able to experience normality while others will remain atypical and marginalized from the experiences of the non-disabled majority. Pandemic time will end and crip time will not. “COVID time is emergency time that has to be endured rather than settled into. We look forward to the passing of COVID time and try not to get comfortable with our new reality. Crip time, in contrast, is planned, built collectively, maintained, and sustained.”[29]

Perhaps, in a post-COVID world, we will retrain some collective knowledge about the ways we experienced pandemic time and how we were able to be flexible and problem-solve, allowing failed attempts to be generative rather than stifling. And maybe, this will lead to more caring and accessible futures for all of us.

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[29] Esther Ignagni, Eliza Chandler & Loree Erickson, “Crips and COVID in Canada” iHuman online: https://www.sheffield.ac.uk/ihuman/covid-19-blog/disability-and-covid-19-global-impacts/crips-and-covid-canada.