



# Activating the arts in death: What are the cultural implications for MAiD?

## Discussion Paper

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### ABSTRACT

This discussion paper attends to subcultural production emerging at the intersection of Medical Assistance in Dying (MAiD), death, disability, and other forms of precarious life. We think with disability arts, that is art created by disabled, mad, sick, and ill people that springs from the experience, politics, and culture of disability (Frazee, 2008) and plays an important role in advancing disability rights and justice. We consider how this form of cultural production animates diverse and intersectional representations and political perspectives in ways that are invitational rather than didactic or prescriptive. By engaging three Canadian disability performance art pieces that activate “crip theory” critical perspectives, we consider how these subcultural productions both indirectly support and extend disability rights endeavours to challenge the implementation of MAiD legislation in Canada. We highlight how each of these works creates space for thinking about the relationship of death and dying in nuanced ways that promote disability life and vitality in a post-MAiD context, without slipping into ableist tropes.

### KEYWORDS

Culture, Death, Disability Art, Disability Rights, Medical Assistance in Dying

### BACKGROUND

#### *Seeing death differently through disability after MAiD*

Amidst the laughter of acclaimed disability artist Liz Carr’s play *Assisted Suicide: The Musical*, rests a moment when the visual description informs the audience that dancers are on stage bearing flags. The description explains that the flags represent nations with legislation sanctioning medical assistance in dying: Switzerland, Colombia, United States, Belgium, the Netherlands, Luxembourg, and, finally, Canada. Watching and listening in the audience, Ignagni and Chandler were sobered by this unwelcome international profile of home.

In 2016, the Medical Assistance in Dying Act (MAiD), following the Supreme Court of Canada’s decision to lift the prohibitions against physician

assisted suicide, was passed into law. On March 11th, 2021, senate passed Bill C-7, an amendment to the Vulnerable Person Standard attached to Canada’s MAiD legislation which broadens the category of health conditions that qualify a person for accessing assisted dying. This higher court ruling was motivated by and complies with a 2019 lower court ruling by the Quebec Superior Court. Subsequent to the passage of Bill C-7, MAiD will be available to people with non-terminal conditions, people with psychiatric disabilities and diagnoses (in two years), and people under the age of 18 (in three years) (CCD, 2021). The amendment will also allow for people to elect for MAiD through advanced directives, and palliative or



home care services are no longer required prior to MAiDs administration (CCD, 2021). Although widely considered a legislative victory and a model for other countries, the passage of MAiD has not been uniformly celebrated. Specifically, MAiD is regarded as a major defeat for disabled peoples and disability movement organizers, who see its significant implications for the treatment and understanding of disabled people within Canada and internationally.

Assisted death debates have historically mobilized disability organizing internationally. Distinct from moral critiques that begin in arguments about the sanctity of life, disability activists have decried MAiD's implicit assumption that a disabled life is devalued, undesirable and unliveable (Kafer, 2013; Frazee, 2014; Michalko, 2002; Titchkosky, 2011). Instead, we in the disability community have pointed to how MAiD exemplifies larger cultural confluences between death and disability. For instance, disabled people's life chances have been systematically limited through the legacy of past eugenic practices of sterilization, institutionalization, and active extermination (Shakespeare, 2010; Malacrida, 2015). Deemed genetically and reproductively inferior, disabled people have and continue to be constructed as threatening to the viability of future generations (Maclaren, 1990; Kevles, 1985; Lombardo, 2008; Dowbiggin, 1997), a construction and representation that spills over into contemporary political, social, and cultural arenas. Social, educational and justice policy, linked with media representations of disabled people as 'mad or bad', construct disabled people as alternately violent, disorderly, a drain on resources and disruptive (Giese, 2016; Watts & Erevelles, 2015). Such understandings fuel calls to contain disabled bodyminds outside of public spaces of everyday life (e.g., Abbas & Voronka, 2014; Parekh, 2014). Moreover, disabled people are constructed in policy, service and research as intensifying the labour of others who risk debilitation through the precarious body-based care labour they perform (Hande & Kelly 2015; Kelly 2016; Gorman 2016; Erevelles, 2011).

These policies, including MAiD, crystallize the denial of the cultural presence of disability. Such denial plays out, for example, in the creeping cultural genocide that results from the restriction of

American Sign Language, British Sign Language and other signed language resources (Paul & Snoddon 2017; LeDuc 2016). Another example of this cultural denial can be found in the maintenance and neglect of inaccessible spaces which fail to anticipate disability and difference, significantly limiting the possibilities for flourishing (Titchkosky, 2011; Preston, 2011). In effect, disabled people are not provided access to life in its myriad enactments - making a life, public life, life-sustaining social and health care resources - even as we are all granted greater access to death through MAiD. MAiD materially and symbolically promulgates disability as a form of social death, a mere temporal space of cultural stasis (Hevey, 2010). At stake for disability activists is MAiD's potential to harden collective understandings of disabled lives as undesirable and/or unliveable that close the public imagination to a vital life with bodymind difference.

## DISCUSSION

Disability advocates, activists, artists, and scholars have attempted to loosen the intertwining of death and disability by promoting our vitality. Through bringing peripheral bodyminds to the centre of critical analysis and cultural production, disabled lives are rendered as valued, vital, and flourishing, in ways that are disruptive to normative neoliberal futures (e.g., McRuer 2006; Chandler & Ignagni, 2018). The conceptual grounding for this reframing is 'crip theory' (McRuer, 2006; Kafer 2013). The theory elaborates on the activist and historical power of the reclaimed term crip. Crip, like queer, holds somewhat contradictory meanings: sometimes marking, other times refusing identities, sometimes working with and against identity politics, sometimes embracing and upholding disability, and other times working to think more than bodily impairment. Crip theory provokes an unsettling analysis, bringing the non-normative bodies and lives that are typically purged from social, political, and cultural life to the very centre of analysis.

The political impulse fuelling calls for "crip futurity" - a future wherein disability is at the center of our analysis - has been to turn away from discussions of death in favour of projects that work to protect disability life, projects such as the acquisition of disability rights and the proliferation



within the cultural sphere with positive representations of disability. Materially, disability advocates point to MAiD's tendency to divert attention away from scarce resources such as state investment in social housing, income supports, attendant and home care provision, community development, elder care and palliative services that promote the survival and flourishing of disabled and other marginalized people. Consequently, discussions of death are elided while collective energies are turned to the struggle for 'access to life' redefining disabled lives as liveable, desirable, and pleasing. Projects such as Not Dead Yet, Project Value, or #WhyUs based in disability pride and vitality, specifically target the necropolitical underpinnings of MAiD by illuminating the generative dimensions of body-mind difference.

The refusal to be understood and depicted dead - as captured in the phrase 'not dead yet' - is complicated by colonialism, racism, sexism, and genderism for many disabled and debilitated people. MAiD and the supportive and detracting movements it engenders, illuminate the unevenly dispersed life and death chances throughout disabled and debilitated populations (Puar, 2017). Movements resisting MAiD may risk calling for normative entry into non-disabled, non-debilitated privileged futures. Fights for disability rights, for example, are often grounded in, seek access to and therefore contribute to neoliberal values, affirmations of a life that necessarily hinges on the eschewing of 'undesirable' lives. In other words, promoting disability vitality and resisting MAiD may involve "projection(s) of bodily capacity" (Puar 2017, p. 17) that ultimately partakes in "slow death" (Berlant, 2007), the wearing down and neglect of precarious populations. We might consider how efforts to redefine disabled lives as 'not dead yet' open populations up to new forms of capacitation as 'objects of care' such as populations living chronically with pain who are made profitable to pharmaceutical industries, care providers, and residential and other services that prolong the temporal period preceding physical death. For instance, MAiD distracts us from the monetization of end of life - particularly through the extension of biological life with profit-generating and painful chemotherapy - that do little to fuel vitality but reinforce end of life as intolerable. MAiD offers a technological solution

to the social problems that accompany bodymind difference, producing new vulnerabilities among those whose lives are already constructed as unworthy or burdensome on others.

Yet, in critiquing the dis/ableist imposition of death, the fullness of what can be learned about death using disability or body-mind difference as an entry to analysis has not been considered. In our work we've been asking how we can promote crip vitality and futurity in a post-MAiD context, without slipping into able-nationalist tropes and succumbing to ableist conceptions of death and dying. We've directed our attention to the subcultural production emerging at the intersection of MAiD, death, disability, and other forms of precarious life to surface "'alternative histories' necessary to a temporal and spatial restructuring of the future and present" (Halberstam, 2011; Fink, 2015, p. 168). In this paper, we engage disability art, that is, art by disabled, mad, sick, and ill people that springs from the experience, politics, and culture of disability (Frazee, 2008). As we have written elsewhere (Ignagni, et al 2019; Chandler & Ignagni, 2018), disability arts play an important role in advancing disability rights and justice for how it publicly animates diverse and intersectional representations and political perspectives in ways that are invitational rather than didactic or prescriptive. To this point, Kelly & Orsini (2016) place disability art in the centre of politics as an "artistic, cultural, and radical intervention" (p. 15), significantly contributing to activist struggles and debates in legal and policy spheres (p. 4).

### *Turning to Disability Arts and Culture*

Thinking about the capacity of art to allow nuanced and political dialogues about death and its relations, we turn to Braidotti (2013) who writes, "art stretches the boundaries of representation to the utmost, it reaches the limits of life itself and thus confronts the horizon of death" (p. 107). From Braidotti, we understand that art can bring us to the vantagepoint of death from which we can assume a critical distance from what we think of as 'human life', allowing us to interrogate the values we assign to our lives. Applying Braidotti's words to the context of disability art, specifically cultural works that animate the intersection of disability, death, and vitality, we take up three works of Canadian



disability arts and cultural practices that mobilize a minute focus on the monstrous mundane, embracing the leaky, abject dying body. We consider these artworks as forces through which to reimagine a present and future history that moves beyond ableist entanglements of disability and death and, in so doing, offer us new ways to think about what can be learned about death from disability.

### ***Posting death: Brianna Hersey (2014-2018)***

From 2014 to her death in March 2018, PhD candidate and artist Brianna Hersey's public Facebook feed offered us a way to intimately witness illness and dying. As 'friends,' we collectively followed her good and bad days, her personal practices of coping and her efforts to navigate a bodymind in flux. Hersey references various physical and psychic troubles: pain, special dietary requirements, infection, and trauma, but never definitively offers (or receives) a diagnosis, avoiding pathographical pitfalls (Couser, 1997). We collectively witness her experiences with the slowing down and wearing out of her physical body in a way that we might recognize as a crip ethic of care (Erickson, 2020). Care flows in all directions in her posts, demystifying illness and dying, offering self-affirming testimony, offering a pedagogy of dying and caring for who will be mourning. Hersey's early posts feature images of her waiting for treatments, celebrating newfound energies as her health improved and pain was better managed. Later, the postings more actively prepare for death: signing an organ donor card, taking up the bureaucracy of leaving one's body to science and instructions for her funeral. Hersey shows us her shunts, her medications, her hair loss, the loss of her body mass, demystifying the markers of 'decline.' Through publicly documenting these changes in reflexive selfies, short videos, and written Facebook posts, Hersey offered a practical element to watching how one crimps death: how we move the peripheral and private experience of caring for oneself and one's dying body to the centre of social presentation of oneself via Facebook. The process of physical change, of new dependencies, shifting functions and appearances are made visible, discussable, commendable, and shareable. Hersey turned the surveillance of Facebook on its head -- crippling the surveillance

of a surveyed body to provide opportunity for public intimacy. Within Hersey's curation of self-portraits - constructed through photographs, videos, messages and longer 'journal' entries - death is not necessarily something to be hastened, but something that can be lived and held together in crip community - communities connected to one another through disability and madness - in interdependence.

Although crip communities are widely dispersed, we are digitally united through social media/Facebook, offering virtual support and attention, recreating a new community commons. Hersey speaks directly to us, her 'friends', offering gratitude for our messages, gifts and good wishes. Through tears of disappointment at her imminent death, Hersey offers us instructions for how to demonstrate our care for her - send flowers, write cards, ask how she is doing, be sad and be grateful. Even as she says goodbye, her posts are generative and creative, mapping new social mores around death and dying, giving rise to new beginnings and connections in digital space, rather than erasure.

### ***Taking it to the grave: Andrew Henderson (2016)***

In another public art practice, *Taking It to The Grave*, queer Canadian artist Andrew Henderson created a performative event, a "living funeral" at Ace Art Inc. arts centre in Winnipeg (Beaudette, 2016). Given weeks to live following a terminal cancer diagnosis, Henderson undertook the art performance to create his own death rituals (Henderson in Beaudette, 2016). In one ritual, Henderson invited the gallery visitors to share secrets with him, 100 of which he had tattooed onto his body, secrets which he would 'take to the grave' (Beaudette, 2016). Provocatively injecting humour into death alongside practical acceptance, Henderson improvises with the ritualistic dimensions of tattoos to mark major life events, transitions, or entry into new communities. He brought a mundane campiness to the tattoo parlour, creating other spaces within the gallery where visitors/audiences could have their nails done (Beaudette, 2016). This expansion of the parlour along with other intimate spaces into the gallery becomes a queer performance of community, a space in which individual bodies are self-stylized even as new intimate bonds - 'eternal ties' - with Henderson are forged through the



sharing of secrets. *Taking It to The Grave* repositions death as relational, breaking down the loneliness and singular experience of death. Henderson's imminent death is generative, offering relief to those who share their secrets without provoking fear. More significantly, Henderson renders death visible in ways that challenge the everyday 'spectacularization of death'.

***Deathnastics: Performed by Sean Lee and Carrie Perreault. Directed by Alex Bulmer. Produced by Esther Ignagni, Eliza Chandler, and Kim Collins. 2018.***

Finally, we turn to our own work in which we activate the arts, the SSHRC funded project Designing Crip Futures in the advent of Medical Assistance in Dying in Canada. Designing Crip Futures uses death cafés and performances to provoke collective and activist reflections on death. We focus our discussion on *Deathnastics*, one research-based performance emerging from this ongoing research in disability cultural approaches to death and dying using death cafés as method.

*Deathnastics* explores the intersection between disability, death, and vitality. Motivated by responses of disability communities to the passage of Canadian MAiD legislation, the project is an extension of our ongoing dedication to representing and advancing disability vitality through disability arts and other cultural practices. In part, the research used death cafés as an intentional space to gather disability community in conversation about political and personal responses to disability and death. Typically, death cafés are loosely structured salon-style conversations related to death, which are often relegated to the private and personal realm, avoided, or silenced within Western/ized communities (Milles & Corr, 2015; Nelson, 2017).

Death café participants respond to prompting questions designed to elicit memories, stories, and reflections. We infuse these death cafes with a disability politic by including questions that draw out the relations between disability and death that we outlined in the first part of this paper. These death cafés create space to acknowledge the materiality of death in disability and mad communities, organize around representations of

disability and death (e.g., public health statistics), foster intersectional and intra-movement coalitional work, and enter conversations about MAiD with one another and our closest allies. Death cafés allow us to engage death in ways that are not individualizing and privatizing, but without an intimate proximity to death.

More recently we have begun to prompt the conversations at our death cafes through short performances that bring to the fore key political issues by animating poignant elements within personal and public stories about death. We are working with Deaf and disabled artists and dramaturgs to develop these performances. *Deathnastics* was the first of this series.

*Deathnastics* was part of Lucy Pallawk and Hazel Meyer's Gymsick performance series at the Bunker of Contemporary Art in early August 2018. We wanted to begin with a story that crystallized the disability rights critique of MAiD; an earlier talk by disability rights leader Catherine Frazee at the University of Ottawa's Centre for Health Law, Policy, and Ethics in 2016 evoked Archie Rolland. Rolland was a man living with ALS in a healthcare institution who accessed MAiD shortly after its legal passage. Drawing from letters Rolland wrote to the Montreal Gazette, Frazee recounted how his unmet basic care needs – switching off the lights when he wanted to sleep, moving his foot when it was uncomfortable, and moistening his lips when they were dry -- led to this decision. Rolland knew that reports of his death would claim, in contradiction to his lived accounts, that the suffering which prompted him to access MAiD was caused by the pain of his impairment.

Archie Rolland's story demonstrates how access to adequate care and access to medical assistance in dying can be imbricated; if you have one, the other becomes unthinkable. In conversation with artist Lindsay Fisher, we decided to animate the quotidian act of moistening lips, through developing an instruction manual for how to moisten lips. Delineating the minute self and other-oriented caring practices of lip moistening in its myriad forms and intentions, the manual became the basis of a short performance that would open, and intentionally animate, one of our death cafés. *Deathnastics* began with instructions for how to moisten your lips to communicate





desire, with instructions like, “Position your tongue at the corner of the mouth. First, slowly draw the tip of your tongue across the upper lip. Repeat with the lower. Ensure that the lick is slow-moving and sensual in action.” Performers Sean Lee and Carrie Perreault, and, in a later iteration, Jack Hawk, would read aloud and perform these instructions. The performance then moved to the type of lip moistening that Rolland required to live, with instructions like, “First, examine the person’s lips and mouth areas closely. Pay special attention to the cracks of the mouth where skin can break down easily. These are the sites where life threatening infection can take hold”. As part of the performative, audience members were invited to ‘try their hand’ at lip moistening - focusing on the technique of their choosing (moistening to communicate desire, moistening to achieve comfort or moistening to provide relief in acute and palliative care).

*Deathnastics* animated the slippage between disability, intimacy, and death, a slippage that was emphasized and explored in the death café conversations held afterwards. For audience members who initially giggled through the descriptions of lip moistening instructions and cheerfully smeared lip balm, honey or petroleum jelly, the café conversation took an abrupt change in tone. The audience members, mostly strangers, engaged in conversations that were first playful recollections about the longing for a kiss in the wake of a break-up, a mother’s wedding day advice to always be wearing lipstick to ‘keep your man,’ and childhood memories of being lip-balmed by a parent before being thrust into a Canadian winter. The stories then moved to more sombre and critical accounts of the gendered demand to smile following surgery to remove a facial tumour; the challenge of securing state care to be adequately fed; and the pain and fear of visiting a publicly funded dentist with life-threatening oral decay. These memories linked mouths, moistening and intimacy, enabling more sober collective reflection on the vulnerability of our bodies and selves.

### IMPLICATIONS FOR MAiD

At the start of this paper, we outlined the social and material implications of MAiD on disabled people and, generally, understandings of disability and

body-mind difference. MAiD maintains our relationships to death as an individual and private matter and enshrines it in the law. We know very little in Canada about the precise circumstances of the more than 8000 people who have elected to use MAiD since its legal passage in 2016. Rhetorically, deaths via MAiD are constructed as upholding individual personhood and self-determination. Moreover, MAiD reinforces the linkages between death and disability in somewhat contradictory ways. First, MAiD reinforces the conflation of death and disability, by positioning a disabled life as not meaningful and devalued, as a life not worth living. Yet, MAiD also prevents the full witnessing of the life-limiting and life-threatening conditions endured by many disabled people. Even as MAiD promises a death with dignity, Black, Indigenous, migrant, poor and trans people - many of whom are disabled or deemed ‘mentally ill’ - continue to struggle and die under dehumanizing and undignified state neglect and direct violence (Hunter-Young, 2017; Sontag, 2003; Millian, 2015). By turning to the cultural practices by Hersey, Henderson and *Deathnastics* and the community-based crip critical perspectives they raise, we attempt to think about death differently through disability. Rather than serving as a justification for death, or as already dead, disability can teach us about the values given to life, or to particular lives. Disability may push us to consider how quality of life is privileged against death. These performances take up death as relational and an opportunity, not a release from life but a release for the living. Where MAiD signals the removal of oneself from the community, neatly relieving others and oneself of the unpredictability and excess of death, the three works presented above go in a different direction. They highlight how disabled and dying people care for others, largely through creating communities - whether in the virtual, gallery or activist spaces.

Drawing again on Braidotti’s (2013) work, these artists offer up death as a vantage point from which we can collectively interrogate life, including life at the boundary of death. These works create spaces – Facebook comment boxes attached to posts, images, and videos of life in close proximity to death, living funerals, and death cafes — wherein we can have communal conversations about disability and death. They bring the



moments which surround death into the realm of public witnessing: Hersey lays bare processes surrounding preparations for death in ways that lifts this temporal period out of strictly logistic and economic concerns; Harrison creates queer death rituals which brings together community and invites collectivity through cultural production; and *Deathnastics* animates the dialectic of death, intimacy, and care into public conversations. Representing and engaging with death through disability enables intimacy with those who might otherwise be strangers and a privileging of much of what is rendered private: mess, bodily exposure, anger and despair, touch, and secrets. By bringing together strangers, a public audience, or a community around death, these performances “unwork” (McKitterick, 2011) the privatization that typically surrounds such matters in normative, western/ized culture. Significantly, they work against this privatization, inviting conviviality by mediating the witnessing and effective engagement with one another’s mortality.

## CONCLUSION

Disability teaches us that we can die as we live, with vulnerability, interdependence, and care. From these crip critical perspectives, we can come together in community and develop more nuanced politics around the ways that MAiD legislation crystalizes disability vitality and precarity.

## REFERENCES

- Abbas, J. & Voronka, J. (2014). Remembering institutional erasures: The meaning of history of disability incarceration in Ontario. In Liat Ben-Moshe, Chris Chapman & Allison C. Carey (Eds.), *Disability incarcerated* (pp. 121-138). New York: Palgrave Macmillan.
- Beaudette, T. (2016, Oct. 11). 'Taking it to the Grave': 28-year-old with terminal cancer plans performance art living funeral. CBC News. Retrieved from: <https://www.cbc.ca/news/canada/manitoba/taking-it-to-the-grave-28-year-old-with-terminal-cancer-plans-performance-art-living-funeral-1.3799098>
- Berlant, L. (2007). Slow death (sovereignty, obesity, lateral agency). *Critical Inquiry*, 33(4), 754-780.
- Bill C-14, An Act to amend the Criminal Code and to make related amendments to other Acts (medical assistance in dying), 42nd Parliament, 1st Session, Canada, 2016, c. 3 (Assented to 17 June 2016), SC 2016, c. 3.
- Braidotti, R. (2013). *The Posthuman*. Cambridge: Polity Press.
- Chandler, E., & Ignagni, E. (2018). Strange beauty: Aesthetic possibilities for desiring disability into the future. In K. Ellis, R. Garland-Thomson, M. Kent, & R. Robertson (eds.) *Interdisciplinary Approaches to Disability* (pp. 255-265). New York: Routledge.
- Council of Canadians with Disabilities (2021, March 12). CCD Disappointed by House of Commons Yes Vote on Bill C-7 (Medical Aid in Dying). <http://www.ccdonline.ca/en/humanrights/endoflife/Media-Release-Bill-C7-12March2021>
- Couser, G. T. (1997). *Recovering bodies: Illness, disability, and life writing*. Madison, WI: University of Wisconsin Press.
- Dowbiggin, I. R. (1997). *Keeping America sane: Psychiatry and eugenics in the United States and Canada, 1880-1940*. Ithaca, NY: Cornell University Press.
- Erevelles, N. (2011). *Disability and difference in global contexts: Enabling a transformative body politic*. New York: Palgrave Macmillan.
- Erickson, L. (2020, June 17). *Thinking about and with Collective Care*. *Cultivating Collective Care*. <https://www.cultivatingcollectivecare.com/post/thinking-about-and-with-collective-care>
- Fink, M. (2015). Don't be a stranger now: Queer exclusions, decarceration, and HIV/AIDS. In OmiSoore H. Dryden and Suzanne Lenon (Eds.), *Disrupting queer inclusion: Canadian homonationalism and the politics of belonging* (pp. 150-168). Vancouver, BC: University of British Columbia Press.
- Frazer, C. (2014, October 14). There can be dignity in all states of life. Ottawa Citizen. <https://ottawacitizen.com/news/national/c>



- atherine-fraze-ee-there-can-be-dignity-in-all-states-of-life
- Giese, R. (2016, June 20). Why integration isn't working for special needs kids—or their classmates. *Today's Parent*. <https://www.todayparent.com/family/special-needs/why-integration-isnt-working-for-special-needs-kids-or-their-classmates/>
- Halberstam, J., & Halberstam, J. (2011). *The queer art of failure*. Durham, NC: Duke University Press.
- Hande, M. J., & Kelly, C. (2015). Organizing survival and resistance in austere times: Shifting disability activism and care politics in Ontario, Canada. *Disability & Society, 30*(7), 961-975.
- Hevey, D. (2010). The enfreakment of photography. In L. Davis (Ed.), *The disability studies reader* (pp. 432-446). New York: Routledge.
- Hunter-Young, N. (2017). Artistic responses to the online proliferation of Black death. Paper presented at Art and Activism: Resilience Techniques in Times of Crisis. Leiden, NL.
- Gorman, R. (2016). Disablement in and for itself: Toward a 'global' idea of disability. *Somatechnics, 6*(2), 249-261.
- Kafer, A. (2013). *Feminist, queer, crip*. Bloomington, IN: Indiana University Press.
- Kelly, C. (2016.) Disability culture and politics: The challenge of direct funding. Vancouver, BC: University of British Columbia Press.
- Kelly, C., & Orsini, M. (Eds.). (2016). *Mobilizing metaphor: Art, culture, and disability activism in Canada*. UBC Press.
- Kevles, D. J. (1995). *In the name of eugenics: Genetics and the uses of human heredity* (No. 95). Harvard University Press.
- LeDuc, V. (2016). "It Fell on Deaf Ears" Deafhood through the graphic signed novel as a form of activism. *Mobilizing Metaphor: Art, Culture, and Disability Activism in Canada*, 118.
- Lombardo, P. A. (2008). *Three generations, no imbeciles: Eugenics, the Supreme Court, and Buck v. Bell*. Baltimore, MD: JHU Press.
- Malacrida, C. (2015). A special hell: Institutional life in Alberta's eugenic years. Toronto, ON: University of Toronto Press.
- McKittrick, K. (2011). On plantations, prisons, and a black sense of place. *Social & Cultural Geography, 12*(8), 947-963.
- McLaren, A. (1990). *Our own master race: Eugenics in Canada, 1885-1945*. Toronto, ON: University of Toronto Press.
- McRuer, R. (2006). *Crip theory: cultural signs of queerness and disability*. University Press.
- Michalko, R. (2002). *The difference that disability makes*. Philadelphia, PA: Temple University Press.
- Million, D. (2013). *Therapeutic nations: Healing in an age of indigenous human rights*. Tucson, AZ: University of Arizona Press.
- Miles, L., & Corr, C. A. (2017). Death cafe: What is it and what we can learn from it. *OMEGA-Journal of Death and Dying, 75*(2), 151-165.
- Nelson, R. (2017). Discussing death over coffee and cake: The emergence of the Death Café. *AJN The American Journal of Nursing, 117*(2), 18-19.
- Parekh, G. G. (2014). *Social citizenship and disability: Identity, belonging, and the structural organization of education*. <https://yorkspace.library.yorku.ca/xmlui/handle/10315/28217>
- Paul, J., & Snodden, K. (2017). Framing Deaf children's right to sign language in the Canadian Charter of Rights and Freedoms. *Canadian Journal of Disability Studies, 6*(1).
- Preston, J. (2011, April 18). Operation: Stairbomb London. <http://www.jeffpreston.ca/2011/04/18/operation-stairbomb-london/>
- Puar, J. K. (2017). *The right to maim: Debility, capacity, disability*. Durham, NC: Duke University Press.
- Shakespeare, T. (2010). The social model of disability. In L. Davis, (Ed.), *The disability studies reader* (pp. 214-221). New York: Routledge.
- Sontag, S. (2003). *Regarding the pain of others*. *Diogenes, 1*(1), 127-139.
- Titchkosky, T. (2011). *The question of access: Disability, space, meaning*. Toronto, ON: University of Toronto Press.





University of Ottawa Centre for Health Law, Policy and Ethics (2016). Ottawa Conference on Medical Assistance in Dying 2016 – Part 1.

<https://www.youtube.com/watch?v=QVW2YTtFSrc>

Watts, I. E., & Erevelles, N. (2004). These deadly times: Reconceptualizing school violence by using critical race theory and disability studies. *American Educational Research Journal*, 41(2), 271-299.