

dispatches from DISABLED COUNTRY

CONTENTS

ix Foreword

Kathryn Church and Melanie Panitch

xv Preface: About Disabled Country

Catherine Frazee

3 Introduction

Christine Kelly and Michael Orsini

REFUSING EXTINCTION

12 Introduction

Harvey Max Chochinov

**17 Death in Disabled Country: Declaring Ourselves
in the MAiD Debate**

**31 Under the Microscope: Dissecting Law and Medicine
in the Disability Rights Laboratory**

42 Disability and Law: Rethinking Paradigms

46 Vigils for Tracy Latimer

**52 Vulnerability and Inducement: Locating the Cart
and the Horse**

**59 Disability Studies: The Genetic Counsellor's
Unexpected Guest**

71 Lamb Affidavit

DISRUPTING CULTURE

- 90 **Introduction**
Eliza Chandler
- 102 **Art with Attitude**
- 106 **Because We Are: Anthem for Disabled Country**
- 110 **Kicking the Applecart, Upsetting Culture**
- 116 **Absent Presence: Disability in (and out of) the Museum**
- 126 ***Stelco's Cabin*, a Response**
- 131 **Contributing to Culture**
- 137 ***Out from Under*: Two Beginnings**

UNMAKING VULNERABILITY

- 146 **Introduction**
Laverne Jacobs
- 153 **Violence, Disability, and Remembering**
- 160 **Courageous States**
- 165 **Disability in a Dangerous Time**
- 175 **Venom without Malice: On First Meeting a Rattlesnake**
- 179 **Separate but Equal, Isn't**
- 186 **Activism Works**
- 190 **Why Monsters Matter: Portrait of the Activist as a Young Monster**
- 195 **Conclusion: An Interview with Catherine Frazee**
Michael Orsini and Christine Kelly
- 231 **Acknowledgments**
- 232 **Notes**
- 239 **References**
- 254 **Contributors**
- 256 **Index**

Introduction

Harvey Max Chochinov

I first met Catherine Frazee as I imagine many people do – by way of video conferencing, as travel can be logistically challenging due to inaccessibility. She appeared to me as a small figure, on a somewhat grainy screen, looking, as I recall, rather fragile and encumbered. If memory serves me correct, there was a woman with her who helped adjust her headset microphone and position her wheelchair. I knew nothing about Catherine, aside from the fact I had been told she was a disability rights activist and scholar. In recalling that first encounter, likely sometime in 2012, I ask myself, What assumptions did I make about Catherine Frazee? This is the question she puts to each of us in this collection.

I thought I knew a lot about Disabled Country. My late sister, Ellen, had cerebral palsy and lived with myriad physical, psychological, and social consequences from her multiple disabilities. I remember taking on a special project in my pre-medical school days, delving into the intricacies of peri-anoxic brain damage and its neurophysiological consequences, based on the location of an anatomical lesion. If only I had known Catherine Frazee back then. She could have

explained that while medicine has found ways to explain and categorize the specifics of cerebral palsy, "This no more describes [the] experience of disability than does the medical description of puberty describe what it means to be thirteen years old" (p. 43).

When I grew up, wheelchairs, Hoyer lifts, bed-pans, surgeries, braces, social workers, physiotherapists, occupational therapists, psychologists, doctors, doctors, and more doctors were part of the background noise of my family's everyday life. They are the external trappings of disability; admittedly, I spent less time contemplating the lived experience of what it might mean or feel like to be disabled. I understood disability in my head, but in hindsight I realize I failed to understand disability in my bones. I was, after all, a young, able-bodied, white male who, Catherine would say, walks, "in that quaint (if somewhat laborious) biped way" (p. 43).

My formal education in the landscape of Disabled Country began with a study (Vulnerable Persons and End of Life New Emerging Team [VP-NET]) funded by the Canadian Institutes of Health Research that delved into issues related to vulnerability, disability, and end-of-life care. Little did I realize I was walking into a cultural, historical, and political minefield, where language, assumptions, and attitudes, including my own, would be put under a microscope. Even the word "vulnerability" turned out to be highly contested, given, as Catherine argues, it is as much a matter of context as it is of personal condition. As she so aptly articulates, "While disabled people are unique, unusual, and

even at times extraordinary, we are not the *other* – falling short of some unspoken threshold. We are fully human” (p. 45) – “complete, complex and undiminished” (Walker 1983, 85). And yet, how often do we perceive their lives to be diminished or somehow biologically inferior? How often do we intuit suffering, not realizing that our own naive ideas about what it means to be “normal” impose suffering, marginalization, and exclusion, resulting in “social barriers and deeply entrenched patterns of discrimination” (p. 65)? As Catherine reminds us, we live “in a social order premised in the most fundamental ways upon the assumption that everyone – or everyone who counts ... walk[s]” (p. 43).

Jim Derksen, a nonwalker, was a fellow VP-NET investigator, postpolio survivor and founder of the Council of Canadians with Disabilities. I recall him gently but firmly taking me to task one day for using the term “wheelchair-bound.” “Harvey,” he said, “I am not wheelchair-bound. I am wheelchair-liberated,” and, indeed, as a wheelchair user, he’d travelled the country and helped entrench disability rights into the Canadian Charter of Rights and Freedoms. Another colleague took exception to the term “artificial nutrition and hydration.” “What do you call that goop inserted into your feeding tube every day at noon,” I asked? His response: “Lunch”! Language, I learned, both reveals and shapes attitudes.

I don’t recall what my assumptions were when I first met with Catherine in 2012. She’d been invited to be a key informant for the VP-NET study. What I can say with certainty is that the moment she began to speak, it was clear to me

that her words, thoughts, and ideas were profound and compelling. We were destined to meet again as a result of a landmark decision by the Supreme Court of Canada (*Carter v Canada (Attorney General)*), in which the prohibition against assisted suicide was deemed contrary to the Canadian Charter of Rights and Freedoms. The court struck down this provision in the Criminal Code, thereby giving mentally competent Canadian adults experiencing intolerable and enduring suffering the right to a physician-hastened death. This ruling overturned the Supreme Court's 1993 ruling in *Rodriguez v British Columbia (AG)*, which denied the right to assisted suicide. The court suspended its ruling for over a year, giving the federal government time to consider legislation that would comply with the ruling. To help define its response to the court's decision, the federal government struck an external panel to study possible legislative responses to *Carter v Canada*. Catherine was the first person to agree to sit on this panel, and I was asked to chair. Working with Catherine during those arduous months we spent exploring issues related to physician-hastened death was one of the most demanding, riveting, and gratifying professional experiences of my life. Much of the credit for that goes to Catherine Frazee. Her intelligence, her passion, her commitment were invigorating and inspiring. I suspect her voice, perhaps more so than any other Canadian's, moved the government to strike the right balance between considering the personal autonomy for those seeking access to medically assisted dying and protecting people who, by virtue of condition and circumstance, have become vulnerable.

You are about to enter into Disabled Country. I wish I had taken the tour so much earlier; it certainly would have helped me understand my sister Ellen better. While I know she suffered, I also know that suffering did not define the essence of who she was, and it was often the result of limited opportunity, resources, and accommodation. When she was on a dance floor, the only people who suffered were those whose toes she managed to crush under the considerable weight of her electric wheelchair. Knowing Catherine as I do, I can say with absolute certainty that you could not have asked for a better, wiser, or more skilled guide. Some of the things she'll show you may be hard to look at. But as she takes you into her world, the one thing you can't afford not to look at is yourself.

DEATH IN DISABLED COUNTRY

Declaring Ourselves in the MAiD Debate

Keynote address, Canadian Disability Studies Association, Congress 2017, "The Next 150, On Indigenous Lands," June 2, 2017

I wrote this piece in the spring of 2017 as a keynote lecture for the Canadian Disability Studies Association annual conference, hosted at what was then known as Ryerson University and is now the Metropolitan University of Toronto. To my knowledge, it is the last lecture-length public presentation of my career – all my more recent work being in shorter formats for panels and mini keynotes that fit more comfortably with my stamina and style of thought. When I look back now, it feels very satisfying to have completed this passage of retirement in the company of my dearest colleagues, at my home university, with a generous invitation to reflect on what had become over the preceding two decades a singular and at times all-consuming concern about where Canada is headed with its long-standing ambivalence about the value of disabled life and, in recent years, its reckless embrace of state-sanctioned assisted suicide.

At the time of this presentation, medical assistance in dying (MAiD) had been legal for less than a year and was restricted to persons who were approaching the end of life. We had fought a gruelling campaign to achieve this bulwark protection, but our success would prove to be short-lived. A challenge to the requirement for "reasonably foreseeable natural death" had been launched ten days after passage of the new law by Julia Lamb, a disabled woman from British Columbia. A similar challenge that would ultimately prove fatal to our efforts – the Truchon case – would be filed two weeks after the presentation was delivered, determining my agenda for disability rights engagement through

to the time of this book's publication, and likely beyond. Our work had only just begun.



I speak this morning from the ancestral and unceded territory of the Mi'kmaq First Nation. I am a settler here, and from this place I offer my words today in the spirit of respect and reconciliation.

I speak this morning with yearning and regret that I could not make the journey to be with you in person. I am sorry for that. If years of life can be measured by their imprint upon us, my time at Ryerson ranks as the most deeply welcoming, the most personally consequential, and the most downright exhilarating decade of my life. For me, and equally for my partner, Patricia, the spectacular circle of scholars and artists and activists – alive and remembered – from Disability Studies at Ryerson are held dear as family.

I speak as well with gratitude to the Canadian Disability Studies Association for the invitation that connects us this morning. Reaching across geography and time, you have entrusted a precious forty-five minutes from a dense and brilliant conference program to a reclusive old white woman who spends almost as much time birdwatching as she does trying to change the world these days. That's a great leap of faith, and I shall try my very best to honour your faith by tempering the presumptions of advocacy with a birdwatcher's humility.

Our conference organizers have challenged us to “creatively imagine disability into our collective future,” so I shall take that as my starting point for this presentation. This act of imagination for me begins in a place called Disabled Country, in the anthemic work of American poet Neil Marcus (1996). Interestingly, and with a certain irony that fits this occasion, it is a settler's poem.

If there was a country called disabled, I would be from there.

I live disabled culture, eat disabled food, make disabled love,

*cry disabled tears, climb disabled mountains and tell
disabled stories.*

*If there was a country called disabled,
Then I am one of its citizens. I came there at age 8.
I tried to leave.
Was encouraged by doctors to leave. I tried to surgically
remove myself from disabled country but found myself,
in the end,
staying and living there.*

It's not the typical colonial narrative, the kind that inspires big anniversary parties at half-century intervals.¹ It is a claiming of place but not territory, a chronicle of trauma, resistance, and, ultimately, something that we might call disabled roots. As Neil Marcus did, we find ourselves "in the end, staying and living there."

Disabled Country. Staying there. Living there. And, yes, dying there.

That's going to be my focus for the next thirty minutes: death in Disabled Country. Death is something I've thought about a great deal over the past few years. I've thought about it in part because of my own inexorable journey into the wild unknown of Disabled Country, in my own process of adapting to and embracing the stubborn decrepitude of age. I've thought about it, of course, as cherished comrades, in recent months, have quietly succumbed to death, taking their final leave from Disabled Country (Brooks 2017). And I have thought about it as well because, as you all know, death is very much a live policy issue in Canada. It's that live policy issue, and the weave of its intersections with our personal and social selves, that I want to focus on this morning. To do that, let's begin with a quick canvas of the death landscape.

Canada has laws about death. The oldest of these laws, the Criminal Code, has been with us since 1892.² The newest of these laws arrived in June of last year.³ The elder law prohibits directly or indirectly causing the death of another human being, full stop. The younger law carves out an exemption in the elder law, making it permissible for particular persons – doctors and nurse practitioners

– to deliberately cause the death of other particular persons in particular circumstances and under particular conditions.

I'll come back to that younger law momentarily. But first I want to step back and acknowledge that the Criminal Code proved itself to be a good old law twenty years ago when the Supreme Court of Canada upheld a murder conviction in a case that had sent shock waves through Disabled Country (Sobsey 1995; CCD, n.d., "Latimer Archives"). Robert Latimer, many of you will recall, had taken the life of his disabled daughter Tracy one autumn morning on a farm in Saskatchewan.⁴ He freely admitted his actions in doing so but resolutely denied any wrongdoing because, in his words, "no one in their right mind would want to exist in that kind of condition" (Dussault 2011). Tracy, who was twelve years old, had cerebral palsy and was unable to speak for herself, at least in conventional ways. The judge who presided over the lower court trial described Tracy's murder as a *compassionate* homicide, "committed for caring and altruistic reasons" (CBC News 2011). And to our collective disabled horror, at least 73 percent of Canadians (Ipsos 1999), by some accounts perhaps as many as 92 percent, agreed (Sobsey 1995).⁵

The story of Tracy Latimer's murder and the long hard fight to have her father convicted for his crime took on epic proportions in Disabled Country in the 1990s.⁶ For Tracy, we cried disabled tears, raged disabled rage, and shared disabled stories. Our stories – disabled stories – proclaimed themselves in sharp contrast to the very different stories of a heroic father's love and the nightmare of a child's afflictions. Those latter stories – the dominant, justificatory stories – besieged us daily in Disabled Country (see, for example, Jenish and Fennell 1994; Corelli, 1994; CBC News 2010), as the Robert Latimer brand took hold in a Canadian psyche that understood nothing about Tracy apart from her surgeries, her impairments, and her pain.⁷

We knew this was dire. Siege was the zeitgeist of Disabled Country in the Latimer decade (see, for example, Kaiser 2001). Three weeks after the verdict in Latimer's first trial, a copycat-style murder felled sixteen-year-old Ryan Wilkieson, who also had cerebral palsy (Canadian Press 1994). Scholars like Sally Hayward

(2009) and Dick Sobsey (1995) published compelling research revealing how cultural narratives that dehumanized a disabled victim would “accelerate the forces that ensure future violence and more deaths” (Sobsey 1995). We took that knowledge to marches, to vigils, to media scrums, and ultimately to court.

In court, in the end, we were heard. After a gruelling seven-year battle, Tracy Latimer’s death would be called by the name of murder and her killer would serve his time.⁸ We had won the battle of justice for Tracy. But the larger victory in the war of idea and allegiance had eluded us, and we knew it. As the battle-weary forces of Disabled Country returned home to disabled mountain and metropolis, a gathering storm of ableist “rightness” still hung in the air.

I speak of “rightness” as Arthur Frank has used the term. In a recent Hastings Centre commentary, Frank wrote that:

Rightness emerges from the fabric of a life – including the economy of its geography, the events of its times, its popular culture – to be what the sociologist Pierre Bourdieu calls a predisposition. It is the product of a way of life and presupposes continuing to live that way ...

[Every moral] actors’ sense of rightness predisposes what their seeing sees and hearing hears; rightness selects what is taken seriously as meaningful versus what is dismissed as noise. (Frank 2017, 1)

Outside the borders of Disabled Country, our impassioned eloquence, our impeccable research, our strategic messaging, our self-evident claim for equal protection of the law – all of it, it turned out, was mostly just noise. It was noise filtered out by the predisposition for looks and lifestyles far more familiar than Tracy’s, a predisposition for the Canadian motif of a man who works the land, provides for his family, and makes the hard choices that duty and honour demand.

Latimer was a sucker punch to those of us who lived comfortable lives in Disabled Country. It struck hard, and fast as lightning. But slower to pierce our consciousness was awakening to the role

that whiteness played in the collective Canadian embrace of Robert Latimer's rightness.

I think it's fair to say, reflecting back on the Latimer years, that the politics of Disabled Country were far from fully woke. We had not seen at first that in the court of public opinion, Robert Latimer was on trial for a lesser category of "white crime" – that is, where a perpetrator who conforms to a public standard of upright citizen causes harm to a victim perceived as derelict or diminished.⁹ "Salt of the earth," when used, as it was, to describe Robert Latimer, meant hard-working, self-reliant, male, and white.¹⁰

Failing to reckon with whiteness as an insidious dimension of rightness elicits breaches of solidarity for which we must ultimately be called to account. When Brian Sinclair died from neglect in a Winnipeg hospital waiting room in 2013, we were deeply troubled, but we did not rage as we had for Tracy (Puxley 2013).¹¹ When residential school survivor Mary Coon-Come recalled the death of Juliet Rabbitskin in her testimony before the Truth and Reconciliation Commission of Canada (2015), we did not rise up and come together in vigil and remembrance. When Andrew Loku was gunned down by police as he stood in the corridor of his West Toronto apartment building, the deadly shots did not reverberate as they should have through every corner of Disabled Country (Warnica 2017).

The Criminal Code may have proved itself a "good old law" back in the days of Robert Latimer, but we had to show up, to shine the light, to make the case for that old law to work. As we well know, justice doesn't arrive at our doorstep like a stray cat. Nor is it like Wheel-Trans, generally reliable but often late. Justice is something we wrangle, a wild and powerful horse most beautiful in full stride but needing to be carefully trained if ever to be harnessed for public good.

If any law, however old, however new, is to protect our lives and respect our ways of being in the nations of the world where the settlers of Disabled Country make our homes, we cannot let the distortions of whiteness or ableist rightness dull our acuity or restrain us from showing up and declaring ourselves. Declaring.

Ourselves. Together. The law – with active wrangling – must protect all of us, whether our form of life resembles that of Tracy Latimer, Brian Sinclair, Juliet Rabbitskin, or Andrew Loku.

With that in mind, let us consider our collective future in relation to the now one-year-old amendment to the Criminal Code permitting medical assistance in dying. Under its narrow exemption to the category of murder, if you are an adult, meaning eighteen years of age or over, if you are suffering intolerably, if you give explicit and informed consent, if you have legal capacity, and if you are dying – the legal requirement is that your “natural death” must be “reasonably foreseeable” – if all of these conditions are met, then the amendment applies. A doctor or nurse practitioner can take active measures to stop the beating of your heart.

That’s a lot of ifs!

Not surprisingly, each one of those “ifs” is contested and controversial. The very existence of this law is contested and controversial, and I expect that a very crude polling at this conference would reveal positions running the full spectrum, from those, on the one hand, who believe that a regulated practice of assisted dying is progressive, humane, and consistent with respect for human autonomy, to those, on the other hand, who believe that it represents an assault to the very heart of our social contract, an ominous abandonment of our ethical moorings and communitarian values. I’m guessing there would be a few “undecideds” in the mix, but probably not many.

But the fact of the law is no longer up for debate. It’s the ifs that open up the field right now for active tussle. In particular:

- ▶ Should “mature minors” have access to assisted death? A formal study is underway (Council of Canadian Academies 2018).
- ▶ Should persons who suffer in ways that are intolerable to them as a result of a mental health condition, but who are not dying, have access to an assisted death? A formal study is underway (ibid.).
- ▶ Should persons with cognitive impairments such as Alzheimer’s, who have lost the capacity to express their wishes or give legal

consent, have access to assisted death if they previously made a formal request by advance directive? You guessed it, a formal study is underway (ibid.).

- Should persons who suffer in ways that are intolerable to them but whose death is not reasonably foreseeable have access to an assisted death? A case is currently before the courts, filed on behalf of a young disabled woman named Julia Lamb (BC Civil Liberties Association 2016).

The day before I recorded this lecture, another plaintiff by the name of Robyn Moro joined this case (Bryden 2017; BC Civil Liberties Association 2017). Moro has Parkinson's disease. Julia Lamb, according to the *Globe and Mail*, is "a wheelchair-bound 26-year-old who suffers from ... a degenerative disease that she fears will eventually consign her to years of unbearable suffering, unable to use her hands, breathe without a ventilator or eat without a feeding tube" (Stone and Fine 2016). I do not know if Ms. Lamb would endorse this description, but I do know that she and I share the same diagnosis and therefore the same prognosis, meaning that I am the sixty-three-year-old version of the future she contemplates.

Full disclosure: Julia Lamb and I do not agree on the question that her case will bring before the court. I am opposed to expanding the reach of doctor-assisted dying. I support vigorous oversight of how the current law is implemented along with rigorous monitoring of its impacts and implications. Full stop.

Reasonable people disagree on whether the current law goes too far or not far enough. But studies are underway, and a keynote podium should not be a soapbox. Accordingly, because the imagining of futures is properly a collective enterprise, I would like to take the remaining time that we have together to sketch out five propositions about which I wonder if perhaps we, the people of Disabled Country and our allies, can agree.

WE HAVE SKIN IN THIS GAME

Literally. A law that sanctions, in certain circumstances, ending the life of a person who has an illness, disease, or disability and

explicitly prohibits ending the life of a person who does not have an illness, disease, or disability is, by definition, a law ABOUT US.

And ... all together now ... NOTHING ABOUT US, WITHOUT US!

What flows from this, and should be self-evident, is that we must be at the table when the issues are studied, in the courtroom when the law is challenged, and in the conversation when the news cycle beckons. But “self-evident” is never a slam dunk in the affairs of Disabled Country. The fourteen-person expert panel of academics currently studying the issue of assisted death where mental illness is the sole underlying condition does not, to my knowledge, include a Mad Studies perspective (Council of Canadian Academies 2018). The application by the Council of Canadians with Disabilities and the Canadian Association for Community Living to intervene in Julia Lamb’s court challenge will be strongly contested by Ms. Lamb’s litigation partners, the BC Civil Liberties Association. And none of our telephones are ringing off the hook from reporters eager to probe the nuance of our thinking on these issues.

Now, of course, none of that will stop us. Because we have skin in this game, the people of Disabled Country will keep on showing up, refining our positions, and declaring ourselves in these debates. We will elbow our way into the discourse, creating our own spaces, tables, and buzz. Grassroots initiatives like the current work of the Empowerment Council (n.d.) at the Centre for Addiction and Mental Health, for example, and the Project Value online community are encouraging signs that there is movement on the ground and places for activists, scholars, and artists to plug in and power up for what promises to be a raucous policy debate (Broverman 2016).

I think we can agree, at the very least, that we can’t afford to sit this one out.

My second proposition is a wee bit more controversial, but here goes.

WE HAVE BAGGAGE TO CARRY ON

When you travel through Disabled Country, there is always baggage. And some of that baggage will not fit neatly into the overhead

compartment. I'm talking about the baggage of history, which is big, and messy, and when it comes to euthanasia, pretty unpleasant. The Latimer story is part of this history, but Latimer itself had antecedents in prewar Germany, when another father, this one in Leipzig, petitioned state authorities to end the life of his disabled child (Gallagher 1995; Evans 2004). Those were the early days in the Nazi enterprise, but the deed was done in the full light of day and with the cooperation and active choices of parents, physicians, and health administrators. And others followed. And things got more covert and out of hand, and hundreds of thousands of our people fell victim to ideas that had first taken root in the rightness of a merciful death (United States Holocaust Memorial Museum 2020a, 2020b; Wikipedia, n.d.).

I know that reference to the Nazi euthanasia program is often heard as strident and hyperbolic. But my point in naming this baggage is not to invoke the inevitability of a slide to atrocity. My point is to invite history along on our journey so that we remain awake and watchful. Simple narratives of mercy and choice are in fact too simple for complicated times. The beguiling glove of what Rosemarie Garland-Thomson (2020) calls velvet eugenics can far too comfortably fit the hand of ideologies of austerity and nationalism. We need to go forward with our eyes wide open to that fact.

We carry the baggage of historical fact. People of Disabled Country have been killed or otherwise harmed, sometimes in great numbers. Too often, doctors have committed these crimes (e.g., Fine 2017). Too often, doctors have acted with the authority of the state (Seidelman 1996). Sometimes, an entire nation colludes. Those who would forbid us to invoke this history, can only fuel doubt about whether its lessons have been learned (see Frazee 2017).

Nothing in the world is ahistorical, least of all euthanasia and assisted suicide. As Geoffrey Reaume (2012, 58–59) wrote, “Historical memory does not ensure citizenship rights, but it can help to promote and protect rights by reminding us of what happens when such rights are curtailed, or worse, utterly denied.”

So let's not leave our important baggage behind.

My third proposition:

WE HAVE TO READ BETWEEN THE LINES

Because a lot gets lost – or added – in translation. The meaning of “reasonably foreseeable natural death,” for example, leaves many of us whose parents were told we wouldn’t survive into adolescence wondering how this sliding scale works. Have our deaths been reasonably foreseeable for thirty, forty, or fifty years, or does it depend on which doctor we ask? Either way, there’s a problem.

The problem is that almost always, when we read between the lines, there is ableism – or its confederates, sanism and audism. My proposition is that we be on high alert for their trickery.

James Cherney (2011) reminded us that “ableist culture sustains and perpetuates itself via rhetoric.” Ableism crashes the party in Disabled Country by transmitting and reproducing itself through language, image, and story. For example, the assisted dying debate is loaded with a highly theatrical rhetoric of ableism – think of the “noble death” film genre: *Whose Life Is It Anyway?* ... *Million Dollar Baby* ... *Me before You*. Every time the camera pans to one of our pitiful bodies being assisted in the shower or hanging by a sling in the air, every time the music swells as one of us shuffles off our mortal coil, what’s the take-away? That we live exquisitely interdependent, undiminished lives? No, these are portraits of our wide-screen suffering, portraits pretty much in keeping with the predispositions of our time (Gilbey 2016).

Ableism seeps into every corner of our lives; it infects our thinking and our discourse, twisting words and phrases like “human rights,” “equal benefit,” “freedom and autonomy.” Last July in Quebec, a man named Archie Rolland requested and received a medically assisted death, after declaring repeatedly and publicly that the staff of his long-term care facility “don’t understand ALS and can’t look after me. It is unbearable” (Fidelman 2016). Only an ableist distortion of autonomy could interpret Archie Rolland’s death in such circumstances to have been freely chosen.¹²

Have there been other deaths like Archie’s, infused with the toxins of ableism?

Perhaps, but here follows the fourth proposition:

WE CANNOT DO THIS IN A VACUUM

More than 1,300 people have died under the Criminal Code exemption for assisted death since the practice became legal in Canada (Ireland 2017). About them we know ... virtually nothing.¹³ We do not know about race or disability status, about ancestry, gender identity, sexual orientation, communication mode, housing status, support arrangements, food and income security, or access to palliative care. We do not know what reasons these persons have given for seeking an assisted death. Most importantly, we do not know what forces of rightness swirled in the air around those choices.

What we do know is that ableism kills. We know it kills in countless insidious ways, by creating conditions which breed illness, fear, and despair, and by its relentless erosion of our resilience. We know that ableism isolates us and undermines our sense of value. That ableism silences us, smothers us in insecurity and presses us toward surrender. We, the people of Disabled Country, know that ableism offers a full menu of inducements to assisted death.

We cannot do vigilance in the dark, and that is why the United Nations Committee on the Rights of Persons with Disabilities (2017), reviewing Canada's compliance with the Convention on the Rights of Persons with Disabilities a few weeks ago issued a strong call for our government to "establish regulations ... requiring collection and reporting of *detailed* information about each request and intervention for MAiD." We must hold our legislators' feet to the fire on this demand.

We cannot do this in a vacuum, but, proposition five:

WE CAN DO THIS

We can do this with scholarship, activism, and solidarity. Let's start with scholarship – research to present in court and to inform the studies that will shape legislative action. Medicine and its empiricist allies have the epistemic advantage on a not-so-level field, but social sciences and humanities – disability, race, and feminist studies, philosophy, history, sociology, rhetoric, and culture –

I cannot stress too forcefully the importance of anti-ableist research from these and other disciplines.

Activism. Taking our art and other activist forms to the public square to push back against all of ableism's rhetorics. Mad art, Crip art, Deaf art – art that affirms and elaborates our flourishing, art that celebrates what is fragile and transient and utterly, gloriously, dependent. In-your-face activism that makes no apology for what we need and how we live, that reaches out to all people of Disabled Country in unqualified welcome, so that they, too, can make themselves at home knowing we will have their back.

Solidarity. A breakthrough solidarity that refuses all of the traps of border control and policing of bodies and behaviour. A solidarity of just relations where my interests and your interests give way to our interests. A solidarity of recognition and mutuality within which we do not call out but call in (Ahmad 2015), when correction is required, like Harriet did with her southern charm when she put it to Peter Singer (McBryde Johnson 2003). We can do this with solidarity that crosses discipline and ideology and does not, to paraphrase Arthur Frank, leave medicine alone to rule the house of dying in Disabled Country (Frank 2007).

CONCLUSION

So here we are at the end of my time, and you have a long day ahead of you. There is so much more to be said about our collective future, yet, in conclusion, I find myself reflecting yet again on the Latimer days.

It took over a decade for me to recognize the racialized subtext of Latimer populism, to see how whiteness operated in the mix. And the more I think about it, the more I realize that there's still more to that case, a deep undercurrent of something that separates our philosophy from what goes on at ground level in the flyover world of Wilkie, Saskatchewan. There are threads to untangle about class and fitness for work and survival; there are epic narratives about snowflake scholars and forgotten people and the fading embers of human decency around the fire we once shared. I can feel the stubble and the cracks of this rupture as if

on dry parchment, but I can't read it yet, and I sure can't lecture about it.

But here we are, on to something new, medical assistance in dying, and it's big and deadly and it's federal, which means whatever we do, it has to work at Yonge and Bloor, but also where the Churchill pours into Reindeer River and also where there is no river and no road, just miles and miles of tundra.¹⁴ And the one thing I know is that we have to figure this out as if someone's life depends on it on it, because, somewhere, it does.

Thank you.

UNDER THE MICROSCOPE

Dissecting Law and Medicine in the Disability Rights Laboratory

*Presentation to the Dalhousie University Health
Law Institute Seminar Series, Halifax, Nova Scotia,
February 9, 2001*

I wrote this lecture for a Dalhousie University Health Law seminar series in February 2001. Twenty years is a long time, and my records and recollections of what led to this no doubt daunting invitation are sparse. In early 2001, I was beginning my transition from previous roles in administrative law and human rights enforcement to a university teaching appointment in the relatively new field of disability studies. I had by this time taught or cotaught a few introductory courses and imagine myself, like a novice dance instructor, learning new steps every week to introduce to my students a few days later. These formative years in disability studies were exhilarating for me, in much the same way as had been my first year of law school. Intoxicated by heady discoveries of bold new framings and frameworks for disability, I would have welcomed this opportunity to pique the curiosity of the scholars and practitioners who would attend the Dalhousie series. As I read my lecture today, I detect an almost breathless compulsion to sample broadly from concepts in law and disability studies that intrigued me and to offer them up as treasure to any worthy explorer of unmapped conceptual terrain.



February 9, 2001

The title that I gave this presentation – regrettably, long before it was written – was “Under the Microscope: Dissecting Law and Medicine in the Disability Rights Laboratory.” It is an extravagant

title, given that I, unlike most of you, have never actually dissected anything in a laboratory – my specialty tends more toward dissecting metaphors. However, with my apologies to those of you who are scientifically schooled, I propose to structure my presentation along the lines of an armchair dissection. I will begin by laying out the two bodies in question – namely, law and medicine – upon the examining table.

With my naked eye, what do I see? Two powerful social forces. Two vastly different academic disciplines. And, parenthetically, a lecture theatre in which are assembled the kith and kin of both, like guests at a wedding. Friends of the law. Friends of medicine. What do they have in common? I begin this enterprise in the disability rights laboratory with a simple rhetorical question: In what ways are law and medicine alike?

My preliminary observations, briefly, are as follows:

Both law and medicine are highly developed intellectual frameworks. They are rigorous, sophisticated, and, for the most part, only superficially accessible to the average person.

Both law and medicine hold in high regard the ideal of a robust constitution.

The enemy of both law and medicine is chaos. Against the ominous chaos of lawlessness, the law draws its sword of reason. Against the dark chaos of illness – and disability – medicine raises its torch of cure.

Both law and medicine incorporate significant investigative components. Inquiry into causation and analysis of relationships of attribution and etiology are of central concern in both disciplines.

Both law and medicine are fundamentally disciplines of persuasion. Legal practitioners use laws of human authority, cases, and argument; medical practitioners use laws of nature, research, and therapies. Legal argument seeks to persuade a judge, through the force of logic and intellectual coherence, appealing to reason. Medical treatment seeks to persuade the body – to cooperate, to perform in accordance with certain agreed-upon norms.

Both law and medicine assign meaning to the human body through metaphors of system and precept. Medicine reads the

body as living matter organized into structural categories (the nervous system, the immune system) and performing functions (respiratory, circulatory, metabolic, and so on). Law reads the body as an idea organized into conceptual categories that confer status (competent, indigent, consenting) or assign social value (eligible, credible, employable, at risk, and so on).

Both law and medicine seek to establish or restore order. The law constructs “justice” as a balanced, harmonious compliance with time-tested rules of human social behaviour. Medicine constructs “health” as a balanced, harmonious compliance with lab-tested rules of human biology and psychology. In other words, the law constructs justice normatively, and medicine constructs health normatively.

From a disability perspective, each is a little too much like the other. Medicine is too quick to judge. And law, too slow to offer curative remedy.

Both law and medicine speak with authority. Each lays claim to being the definitive voice on what is and is not a disability. This of course hails back to the Industrial Revolution, when thousands of people were thrown out of work by the efficiencies of steam. The new Poor Law of Victorian England, aiming to restrict social assistance to only the worthiest poor, first gave the responsibility of judging “worthiness” to magistrates. Fears, however, that many of the unworthy were fraudulently enjoying the state’s free gruel gave rise to a need for “objective” verification of actual inability to work. Medicine – decisively wrested from the hands of the witches and wise women centuries before – was ready to oblige. New tools – microscopes, stethoscopes, x-rays – tools that allowed privileged access to our very insides, were brought to the service of limiting the spread of the welfare state. Still today, the definitional hoops that we must jump through to qualify for the disability tax credit or to secure funding for a wheelchair (even, in my case, a prescription is required) reflect a clear favouring of medical and legal expertise over everyday, commonsense observation.

The processes of law and medicine – at least traditionally – have professed their own absolute neutrality and have denied, avoided, disavowed, and dodged associations with the messy

business of human emotion. To be sure, courtrooms and hospitals – like wedding ceremonies and airports – swirl with the pageant of human emotion. But while passions run high among spectators, witnesses, parties, and patients, the process that they give themselves over to can be expected to repel their heat. At its core, the legal process is coolly, distantly rational, and the medical process is, well, clinical.

Much more can be said about each of these generalizations – much more that will be said in the longer paper that calls to be written, building from the ideas we will be discussing today. For now, this perspective from the naked eye affords a starting point for the exploration promised by my title. Let's proceed to prepare a few tissue samples for more careful attention, beginning with the outermost layer of cells – the figurative epidermis – that part of the body of law and medicine most directly touched by context.

Although I ended my list of characteristics common to both law and medicine with a reference to their historical insistence on standing well back from human passions, the good news is that this detached and impersonal orientation of law and medicine is changing. Radical scholars, critical theorists, reformers, consumers, and activists have contributed to the substantial reforms that we now see in twenty-first-century medicine and law. Increasingly, practitioners of contemporary Western medicine are approaching the patient not as an arbitrary constellation of individual parts and systems but as a unique and integral whole person, whose health status is shaped not only biologically but by a wide range of familial, social, and economic health determinants, including relationships with carers and health advisers. Similarly, the courts have come to recognize the importance of perspective and social context, acknowledging that “the questions of fact and law to be determined in any given case do not arise in a vacuum.”¹

Important guidance on this principle has come from the Supreme Court of Canada in its 1997 decision in *RDS*. Distinguishing between the impartiality that is required of all judges and the fallacy of judicial neutrality, Madam Justices L'Heureux-Dubé and McLachlin, writing for the majority, stated that “a conscious,

contextual inquiry has become an accepted step towards judicial impartiality.”² Citing Jennifer Nedelsky (1997), they explained:

What makes it possible for us to genuinely judge, to move beyond our private idiosyncrasies and preferences, is our capacity to achieve an “enlargement of mind.” We do this by taking different perspectives into account. This is the path out of the blindness of our subjective private conditions. The more views we are able to take into account, the less likely we are to be locked into one perspective ... It is the capacity for “enlargement of mind” that makes autonomous, impartial judgment possible.

Leaving aside for another time Nedelsky’s unfortunate and gratuitous use of a blindness metaphor, there is, indeed, some cause for optimism. Both in law and in medicine we see encouraging signs of greater sensitivity to context. For the most part, from a disability perspective, this is a welcome development. I include the qualifier “for the most part,” recognizing that in a legal context in which ownership of slaves is the norm, contextual inquiry can produce a Dred Scott decision. In a medical context in which bleeding is considered curative, then bloodletting will pass. And in a society in which

- ▶ determinations of quality of life are reduced to calibrations of physiological and intellectual prowess; or where
- ▶ genetic technologies careen towards a human community no longer populated by persons with Down syndrome, dystonia, or SMA; or where
- ▶ parents of children with impairments sue their physicians for wrongful birth and children with impairments sue their parents and physicians both for wrongful life

... in such a society, sensitivity to context may be a double-edged sword.

Accordingly, we in the disability rights laboratory feel compelled to draw another sample – from deeper vascular tissue – to

satisfy ourselves that that which flows beneath the surface of this context is health- and justice-promoting, rather than the opposite.

Returning to the *RDS* decision, we find the following passage from Benjamin Cardozo (1921) cited with approval in the majority decision:

There is in each of us a stream of tendency, whether you choose to call it philosophy or not, which gives coherence and direction to thought and action. Judges cannot escape that current any more than other mortals. All their lives, forces which they do not recognize and cannot name, have been tugging at them – inherited instincts, traditional beliefs, acquired convictions; and the resultant is an outlook on life ... In this mental background every problem finds its setting. We may try to see things as objectively as we please. None the less, we can never see them with any eyes except our own.

This laudable recognition brings into focus the question that will be central at this stage of our dissection exercise: What are those nameless forces of instinct, belief, and conviction tugging at the minds of judges, doctors, academics, and their various protégés in law and medicine?

Catharine MacKinnon, who has written extensively on the relationship between pornography and sexual violence against women, offers some instructive insights into the nature of those nameless forces, how they operate and how they are shaped. According to MacKinnon (Farber and Sherry 1996, 45), society is actually “made of language.” She writes:

Social inequality is substantially created and enforced – that is, *done* – through words and images. Social hierarchy cannot and does not exist without being embodied in meanings and expressed in communications ... Words and images are how people are placed in hierarchies, how social stratification is made to seem inevitable and right, how feelings of inferiority and superiority are

engendered, and how indifference to violence against those on the bottom is rationalized and normalized. Social supremacy is made, inside and between people, through making meanings.

Can MacKinnon's analysis serve us in the disability rights laboratory? Let us take, for example, two contrasting images from the still-pulsing reality of the Tracy Latimer story.

On the one hand, the images of Robert that are embedded in our consciousness from the ten o'clock news are images of a man of the land, rough and rugged like the landscape he inhabits, the land he works with his strong hands and his straight back. Mostly, we see him in winter, his steamy breath reminding us of the harsh realities of survival in an inhospitable environment. Just below the surface runs a current of the ethic of Darwinian survival.

On the other hand, there is Tracy. She is always pictured indoors, although we know that she had to go outside every day into the same elements that Robert so easily and surely stands in – because she went to school. That fact simply does not register. Instead, we are convinced that she was impossibly delicate, fragile, not long for this world, with or without his intervention. Somehow, Tracy does not belong with nature the way that Robert does. And below the surface of her image runs a current of fear – fear of our own vulnerability, fear that we, too, might give birth to such a child, fear of pain.

What I take from the work of scholars like MacKinnon and others working in a similar vein with a critical race analysis of hate speech is that much of what we believe, much of what forms our tacit consensus about the way things are and the way things ought to be, much of what shapes the ideas and beliefs that we have always held and those that are newly held, comes to us not as a result of active, conscious persuasion, but as a result of other forces – forces that operate not at the level of reason but instead more “like a computer virus ... [altering] our programming without our knowledge” (Farber and Sherry 1996, 47). These forces, like a Trojan horse within our popular culture, pose a substantial risk – particularly when they too easily take on the guise of

compassionate sensibility or, worse still, “enlargement of mind” among ethicists, physicians, or jurists.

These Trojan forces are highly prejudicial to the personal and collective claims to equality, health, and justice for people with disabilities. Deep below the level of consciousness, people react negatively – instinctively, viscerally, automatically – to physical difference. Of course, we all have visible physical differences – that is precisely how we are able to tell one another apart. But, by and large, those differences are most comfortably tolerated within a very narrow band – a comfort zone that bodies like mine and Tracy’s transgress wildly. Robert Latimer is positioned well within – perhaps right on – the normative bullseye.

And at the heart of his cause is a deep cultural fear of disability.

Disability, in art and literature, is often employed as a metaphor for evil. We are the opposite of what society – and these two great bodies under examination today – value most highly. We are the chaos, the darkness, jealousy, contingency, loss, failure, and lack of control. Medicine and law – because both professions are populated by culture-soaked consumers of words and images – both prefer the look and feel of that normative reality. Medicine does everything it can to shape and alter the physical “presentation” of people with disabilities – making us as “normal” as possible in form and function. The law does everything in its power to construct the “reasonable person” or, if that being is absent before it, to construct a “substitute” to speak in place of the “incompetent” individual.

Just as MacKinnon argues that “sexism is a mindset that is inculcated through stories that bypass conscious thought,” I would argue that ableist and ultimately eugenic ideas have similar origins and influence (Farber and Sherry 1996, 46). Here, we may have exposed the pathologies encoded in the tissue samples before us – those of both law and medicine.

Perhaps as with pornography and hate speech, an anxious public, including doctors, lawyers, judges, therapists, and others, has been persuaded of the inferiority of a disability status – persuaded not by conscious thought but rather by deep currents

in the river of culture, privilege, and power. Under a disability microscope, this deadly current might well be what MacKinnon calls the “attitudinal engines of the exclusion, denigration and subordination that make up and propel social inequality ... [controlling] access to opportunities more powerfully than ... individual abilities ever do” (Farber and Sherry 1996, 46).

Arthur Frank writes from a position of direct personal experience with dire illness – both heart disease and cancer. He movingly describes the devastation of one’s sense of self, of isolation, physical and psychological pain. Frank describes disease and illness as “unmaking processes” – great holes punched in our notions of all we thought we knew. “Remaking,” he says, “begins when our own suffering becomes an opening to others” (Frank 2013, 176). In the greatest depths of suffering, he perceives the possibility of curative transformation, when suffering invokes attention to the other. According to Frank, the suffering person is always the other, reduced and isolated. The “supreme ethical principle” within human suffering is found when the cry of suffering is actively witnessed and attended to (Frank 2013, 178).

Frank’s powerful personal account provides itself a window through which, perhaps, you will be able to glimpse the meaning of a story I would like to close with – a story that emanates from the fringes of law and medicine, behind the textured curtain of disability.

In an essay recently published in the *Globe and Mail*, entitled “David Means Beloved,” my friend Sandra Shields describes her relationship with her younger brother David, a man of twenty-seven who has profound mental and physical impairments (Shields 2001). Sandra grapples with the deep question of what David’s existence means to her, recalling three distinct encounters. In the first, a nine-year-old Sandra strains to reach her baby brother: “Sitting beside him, I poured all of my thinking and feeling into making sure my little brother got the message ... That even though he was shut in a world of his own, I loved him. ‘If you ever want to tell us something, I’m here. I’ll listen.’”

Now a mature woman in her thirties, Sandra still carries the conviction that David is in there, despite the muddying effect of

“six years of academic philosophy [with its] quality of life arguments and such.”

“In terms of dollars and drugs and pain, it’s hard to justify David. It’s hard to say what being alive means for him.”

David is visited daily by seizures. They are “frightful to watch although they’ve become a familiar enemy, their horror diminished by repetition.” Seizures and medication, bottles and diapers, after twenty-seven years, they are part of the fabric of Sandra and David’s family.

In the second encounter, Sandra and her husband care for David while her parents take a short vacation. She recalls:

Just as evening turned into night, David’s sounds slipped into sadness. His seizures were going through an upswing, leaving him drained and fretful. This night his sorrowful sounds pulled me away from the television. I held his hand, stroked his cheek and watched tiny tremors shake him every few minutes. The tremors seemed to be defeating him, pulling him further and further away.

I wanted to stop them. Curling up behind him, I willed the tremors to end. They didn’t. I lay there holding David for longer than I had in years. I began crying, no sobs, just streaming tears. There was such a huge sadness in my brother that night. It was as if he was mourning what the seizures take – his alertness, his energy, the small space in which he lives and finds pleasure.

In the third and final encounter, Sandra reaches for truth, struggling for an honest account of who David really is – beyond what she fears might be her own projections. She wonders: “Is the bond only in my head and heart? Is there really an answering echo from David’s over-medicated, underdeveloped mind? Did I simply choose the happiest way to deal with a creature who shared my space as I grew up? Was it easier to grant him a small piece of humanity?”

She notices:

When I'm asking these questions, my eyes slide around David. I ignore him. Inevitably, however, I feel I can only answer the questions by being with him again. I sometimes put it off, not because I fear a negative answer, a vacancy too hollow to deny ... I seem to be reluctant to reconnect with David because of what connecting with him is. It's big somehow.

She takes her question to David: "Hey love, what do you think, do I make it all up? David murmured; rolled his head; gnawed on the arm of an old sweatshirt. I don't know what it means, but I wanted badly to hug him. That in itself seemed the answer."

I find most telling the part of the story where Sandra's eyes "slide around David" – her intellectualizing of his being shames her – shames the love that she feels for him. She describes with such honesty that swift current of thought that tugs and pulls below the surface of consciousness.

I do not know how the crude mechanisms of law and medicine can begin to approach the truth of David. Nor do I know how notions of justice, health, and dignity can be shaped by and for David and others who cannot easily speak so that we will understand – others who depend on the enlargement of mind and spirit of people like the ones in this room – people who, through historical, economic, and intellectual privilege, hold so much power over their lives.

It is my hope that law and medicine can continue to be rehabilitated from history, from prejudice, from the dread of chaos. It is my hope that both law and medicine continue to approach this greater enlargement of mind so vital to the survival of David and others. I hope that they will – I believe that they must.

© UBC Press 2023

All rights reserved. No part of this publication may be reproduced, stored in a retrieval system, or transmitted, in any form or by any means, without prior written permission of the publisher.

Library and Archives Canada Cataloguing in Publication

Title: Dispatches from disabled country / by Catherine Frazee ; edited by Christine Kelly and Michael Orsini.

Names: Frazee, Catherine, author. | Kelly, Christine, editor. | Orsini, Michael, editor.

Series: Disability culture and politics.

Description: Series statement: Disability culture and politics | Includes bibliographical references and index.

Identifiers: Canadiana (print) 20230185568 | Canadiana (ebook) 20230185614 |

ISBN 9780774868686 (softcover) | ISBN 9780774868709 (EPUB) | ISBN 9780774868693 (PDF)

Subjects: LCSH: People with disabilities. | LCSH: Disability culture. | LCSH: Artists with disabilities. | LCSH: Assisted suicide.

Classification: LCC HV1568 .F73 2023 | DDC 362.4—dc23



Canada Council
for the Arts

Conseil des arts
du Canada

Canada



BRITISH COLUMBIA
ARTS COUNCIL



BRITISH
COLUMBIA

UBC Press gratefully acknowledges the financial support for our publishing program of the Government of Canada, the Canada Council for the Arts, and the British Columbia Arts Council.

This book has been published with the help of a grant from the Canadian Federation for the Humanities and Social Sciences, through the Awards to Scholarly Publications Program, using funds provided by the Social Sciences and Humanities Research Council of Canada.

UBC Press
The University of British Columbia
2029 West Mall
Vancouver, BC V6T 1Z2
www.ubcpress.ca