**Data, disability and BILL C7:
Case Study introductory remarks**

for
“Designing Proof & evidence
with minorities & outliers”

**a *We Count* initiative**

of the

Inclusive Design Research Centre at OCAD University

Catherine Frazee[[1]](#footnote-1)\*

October 19, 2021

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.

**1. Case Study Background: Bill C-7 and the VPS**

A few months ago, I was part of a small contingent that came to speak with the *We Count* project team on behalf of a larger working group of experts and advisors in disability justice, social policy, law, ethics and medicine who authored and mobilized the [Vulnerable Persons Standard](http://www.vps-npv.ca/) [the VPS] in 2016. The VPS is a detailed policy standard intended to be used as a benchmark for any regime that permits medical assistance in dying, to do so in a way that does not put marginalized, disadvantaged or vulnerable persons at risk of harm or abuse.

We were drawn to approach *We Count* because of legal and political developments triggered by a 2019 Québec court decision [the [Truchon case](http://citoyens.soquij.qc.ca/php/downloadti.php?doc=ABDC24B668988D804B23D496876FB98A&banque=CS&lang=en)] and a subsequent lawmaking process that culminated in the passage of [Bill C-7](https://parl.ca/DocumentViewer/en/43-2/bill/C-7/royal-assent) in March of this year. Many of you know this but just so we are all on the same page, Bill C-7 essentially gutted every pillar of the Vulnerable Persons Standard, by creating a special supplementary pathway to assisted death for persons with “grievous and irremediable medical conditions” – a phrase that effectively – and in practice – includes all persons with incurable disabilities. Prior to the passage of Bill C-7, a person’s natural death had to be reasonably foreseeable in order to be approved for a medically assisted death. This safeguard was and remains a cornerstone principle of the VPS but is no longer a system guardrail to protect disabled persons from suicidal desires or inducements and social pressure to end their lives[[2]](#footnote-2).

As I think everyone here appreciates, Canada’s disability rights and disability justice communities came together with a rather unprecedented level of solidarity to oppose the passage of Bill C-7, and the VPS became part of a vocal and energized resistance seeking to defend the bulwark of a “reasonably foreseeable natural death” threshold for all persons, regardless of disability status. Press conferences, street demonstrations, policy briefs, backroom lobbying, impassioned testimony, round-the-clock vigils – we left it all on the field.

But the Bill passed. And in its final form it was even more nightmarish in its scope, expanding eligibility on the basis of mental health condition, even in the absence of any other disability, illness or disease.

We are still reeling, still regrouping, still gathering strength and resources as we seek to move from reacting and defending to initiating our own litigation and advocacy claims, both domestically and internationally. Like me, many of you are up to your ears in this ongoing, relentless work. And part of that work is the postmortem – coming to an understanding of how, for all of our efforts, we failed to make a dent in the wall of a so-called consensus that this change in the law was overwhelmingly supported by evidence and public opinion shaped by that evidence.

That’s what brought the VPS to *We Count*. It’s right there on the *We Count* [website](https://wecount.inclusivedesign.ca/), which introduces a highly skilled team of people seeking to intervene effectively when groups of people find that “Their needs are either not captured in data, eliminated from the data set as outliers, or overwhelmed by majority data.”

Urgent concerns sidestepped? Check.

Data eliminated from the discussion? Check.

Steamrolled by the majority? Check.

“That’s us”, we said. *We Count* is speaking to us.

And that’s how this all started.

2. **Data Challenge: Bill C-7 and Disability Justice**

For the purposes of this case study, our focus isn’t on policy positions or political strategies, or even whether you support MAiD in its present form or not. Our focus is on the data that ultimately give rise to and support the policy positions and political strategies we choose.

Disability rights defenders were the outliers in the Bill C-7 debates and that fact proved determinative of the outcome of those debates. To tease out the various kinds of data that were overlooked or sidestepped or overruled in our every intervention, we started with the following question:

*What is the evidentiary challenge that our VPS community, and members of a broad and diverse disability rights coalition, faced in the litigation and policy debates leading up to the passage of Bill C-7 – an amendment to Canada’s Criminal Code exemption for medically assisted death?*

Many of you who were as involved as I was will have your own framings of that challenge, but I’ll just take a couple of minutes to suggest what stands out for me.

1. **Decontextualized Data
Data collected by provincial and federal governments to monitor for adverse effects in the MAiD regime fail to capture any measure of ambivalence or injustice that factor in a disabled person’s death by MAiD.** The current monitoring system does not capture the crucial particulars, for example, of Sean Tagert’s final days before his MAiD death[[3]](#footnote-3), during which he continued to plead for the few extra hours of paid homecare that would have saved him from what he called the “death sentence” of a forced removal from his family to an institution hours away from home. Nor does the monitoring system capture the filth and stench of the room in a long-term care institution where Chris Gladders surrendered his life to MAiD[[4]](#footnote-4). Both of these cases simply count as ‘autonomous choices’ made by ‘capable adults’ to end their lives because of intolerable suffering arising from a ‘medical condition’. In other words, the data that would actually differentiate these cases from the paradigm case of an 80-year-old gentleman who dies in his comfortable king-size bed looking out at the sunset after a lobster dinner with his loving family, simply never registers. That’s not monitoring, it’s erasure.
2. **Data Exclusions – “Anecdotes”
When alarming cases[[5]](#footnote-5) – like Sean Tagert, Chris Gladders, Archie Rolland[[6]](#footnote-6), and others, most recently, Rosina Kamis[[7]](#footnote-7) – come to light, most frequently through social media, their particulars are not seen as evidence, but rather anecdote.** The Supreme Court of Canada, in its 2015 judgement in the Carter case – before we had a law permitting MAiD in Canada and were therefore presenting comparable cases from reports in Belgium and the Netherlands – made its position on what counts as evidence very clear. The court wrote: “Anecdotal examples of controversial cases abroad were cited in support of this argument, only to be countered by anecdotal examples of systems that work well. The resolution of the issue before us falls to be resolved not by competing *anecdotes*, but by the *evidence*.”[[8]](#footnote-8) In a sense, we are left to conclude that anecdotes will not be treated as meaningful data, and in evidentiary terms, every anecdote will be given equal weight, whether it describes a privileged life that comes to an idyllic end, or a case of systemic abuse and neglect that ends in a desperate capitulation. And injustice and inequity will prevail in lives relegated to the status of anecdote.
3. **Data Handicapping[[9]](#footnote-9)
Data compiled and published in peer-reviewed journals from international jurisdictions with contemporary assisted dying regimes comparable to Canada’s are dismissed as not relevant.** Presented with evidence of abuses under Belgium’s regime, the Supreme Court of Canada reasoned that “… the permissive regime in Belgium is the product of a very different medico-legal culture.”[[10]](#footnote-10) And that was that for evidence that we had presented concerning the risk, broadly speaking, of the overzealous MAiD physician and the risk of a slide toward more and more permissive MAiD policy. We are thus, it seems, faced with an additional evidentiary burden if we wish to introduce offshore data: proving that Canada’s “medico-legal culture” bears greater similarity to Belgium’s than what was believed to be the case in 2015. But how does one go about gathering evidence of culture? And what novel sandtraps await us as we endeavour to meet the data threshold for such proof?
4. **Data Policing
Much of the evidence that we consider relevant to understanding discriminatory trends and impacts is discounted as baseless, and disparaged as a “slippery slope” argument.** Factual references from history – for example, offering any fact-based analysis of the rise of eugenic practices in North America and Europe – is invariably shut down and often rebuked as irresponsible and hyperbolic[[11]](#footnote-11). By a similar kind of data policing, data drawn from reputable, peer-reviewed calculations of the healthcare cost savings attributable to MAiD (in the range of $35-$139 million annually[[12]](#footnote-12)), or government data showing a steep rise in MAiD cases from year to year (2020 marked a 34% increase over case numbers from 2019[[13]](#footnote-13)) are kept in discrete data silos, not considered as part of a narrowly prescribed field of data deemed relevant to MAiD policy.
5. **Data Discrimination
Data that does not meet a certain unspoken numeric threshold is not given due recognition, even though it comes from populations most directly impacted by MAiD policy.** Put moresimply, if MAiD policymaking is essentially a numbers game, we lose.Throughout that dark and sordid chapter of *Life in Disabled Country[[14]](#footnote-14)* that was Bill C-7, the single most impenetrable narrative that we confronted was that expansion of MAiD to persons with disabling conditions who were not nearing the natural end of their lives was a legislative amendment that enjoyed broad popular support. The Minister of Justice often pointed out that the government had received over 300,000 responses to an online survey and that the Bill reflected a broad consensus in the range of 70%. Yet when we analysed a selected sample of duplicate copies of responses to that same survey filed by VPS supporters, a [different story of stakeholders](https://static1.squarespace.com/static/56bb84cb01dbae77f988b71a/t/5f9065e56d65272858143fca/1603298789807/Voices%2Bfrom%2Bthe%2BMargins.pdf) overwhelmingly opposed to the Bill emerged. But our sample size of 60 – a respectable number for qualitative analysis – was no match for a dataset of 300,000 in quantitative terms. Our contribution to the data remained invisible.
6. **Data Devaluation
When disabled people speak vividly about the social, economic, and stigma-based stresses that undermine the will to live and are a common feature of our life-and-death interactions with medical personnel and healthcare institutions, our submissions are applauded for their *authenticity*, but seen as emotionally cathartic rather than as data**. When Gabrielle Peters[[15]](#footnote-15) spoke to the Standing Senate Committee about the intersections of poverty and disability, when Sarah Jama[[16]](#footnote-16) exposed the systemic racist dimensions of Bill C-7, when Heidi Janz[[17]](#footnote-17) elaborated on her theory of medical ableism in the granular details of an emergency room encounter, Senators teared up and thanked everyone for their heartfelt and authentic submissions, but nothing registered as data.
7. **Data Appropriation
First-person accounts from lived experience are used selectively by policymakers to punctuate or illustrate an established point, but are never viewed as a legitimate basis for policy decisions.** I’ve heard this described as a form of data extraction. It’s a pet peeve of mine, and I don’t believe I’m alone. Our stories, in our voices, are mined and used as a literary interlude, a tool for *policy-writing*, but never a basis for *policy-making*. We therefore find our words and experiences, if used at all, used by apologists to signal their own virtues of compassion or active listening, rather than as data to inform the decisions of elected officials, their policy advisors, and the judges who consider contentious cases. Our vivid and meticulous reports from Ground Zero in the struggle for dignity and equality too often appear as footnotes, rather than data points.
8. **Data Thwarting
Certain policy norms, protocols and cultural conventions – ranging, for example, from patient confidentiality policies, to cultures of silence among self-regulating physicians, to journalistic preferences for uplifting and inspirational stories about disability – operate to thwart our access to data that would reveal injustice and abuse in MAiD practice.** For example, while there is widespread chatter on social media and elsewhere about persons with disabilities driven to MAiD by conditions of unlivable poverty, or young persons in the prime of sexual maturity consenting to MAiD because they despair of ever having a romantic partner, we must rely for data on the faint hope of a physician whistleblower or the trend-bucking efforts of an investigative journalist, or the herculean efforts of a disabled person willing and able to document and disclose the very experience that has extinguished their will to live. We know the data exists, but we are thwarted at every turn from bringing it to light.

And there’s more. More ways in which, when it comes to arguably the most significant Criminal Code amendments ever to directly implicate the lives of people with disabilities, we have been left behind in a cloud of ableist and exclusionary practice in the production, collection and reporting of data.

The good news is that today and in our further deliberations in the coming weeks, we have the opportunity, working in this unique co-design process, to begin to untangle and wrestle with these exclusions.

Thank you to each of you for volunteering your time to help us tackle this data challenge.

1. \* *Catherine Frazee is Professor Emerita in the School of Disability Studies at Ryerson University, and an Advisor to the* [*Vulnerable Persons Standard*](http://www.vps-npv.ca/)*.*  [↑](#footnote-ref-1)
2. For a further commentary on this discriminatory framing, see "[Assisted Dying Legislation Puts Equality for People with Disabilities at Risk](https://www.theglobeandmail.com/opinion/article-assisted-dying-legislation-puts-equality-for-people-with-disabilities/)", Frazee, C., Globe and Mail, November 17, 2020. [↑](#footnote-ref-2)
3. <https://bc.ctvnews.ca/we-need-a-public-outcry-b-c-father-with-als-ends-life-after-struggle-to-stay-at-home-1.4543983> [↑](#footnote-ref-3)
4. https://www.cbc.ca/news/canada/hamilton/greycliff-manor-covid19-1.5891730 [↑](#footnote-ref-4)
5. For more examples of cases that raise serious concerns of abuse and injustice, see "Cases of Concern: [Medical Assistance in Dying and the Inducements of Social Deprivation](https://static1.squarespace.com/static/56bb84cb01dbae77f988b71a/t/615716183c30976483303da6/1633097241515/Updated%2BCases%2Bof%2BConcern%2B.pdf)", Vulnerable Persons Standard, October 2021. [↑](#footnote-ref-5)
6. <https://montrealgazette.com/news/local-news/life-in-long-term-hospital-unbearable-montreal-man-with-als> [↑](#footnote-ref-6)
7. <https://youtu.be/sAFX5bcWt-8> [↑](#footnote-ref-7)
8. [Carter v. Canada](https://scc-csc.lexum.com/scc-csc/scc-csc/en/item/14637/index.do) (Attorney General) [2015] 1 SCR 331 at paragraph 120. [↑](#footnote-ref-8)
9. I use the term here ironically, in the sense of a deliberate disadvantaging by introducing additional hoops to be jumped through. [↑](#footnote-ref-9)
10. ibid., at paragraph 112. [↑](#footnote-ref-10)
11. For an example of this practice, see Frazee, C., "[Assisted Dying and the Lessons of History](nd%20that%20was%20that%20for%20evidence%20that%20we%20had%20presented%20concerning%20the%20risk%2C%20broadly%20speaking%2C%20of%20the%20overzealous%20MAiD%20physician%20and%20the%20risk%20of%20a%20slide%20toward%20more%20and%20more%20permissive%20MAiD%20policy.)". Policy Options, June 6, 2017 [↑](#footnote-ref-11)
12. Trachtenberg, A. and Manns, B., "[Cost analysis of medical assistance in dying in Canada](https://www.cmaj.ca/content/189/3/E101)". CMAJ January 23, 2017 189. [↑](#footnote-ref-12)
13. Health Canada, "[Second Annual Report on Medical Assistance in Dying in Canada 2020](https://www.canada.ca/en/health-canada/services/medical-assistance-dying/annual-report-2020.html#3_1)". June 2021 [↑](#footnote-ref-13)
14. My figurative characterization of Disabled Country is inspired by the poetic work of the same name, composed and performed by Neil Marcus. See <https://everybody.si.edu/place> [↑](#footnote-ref-14)
15. Testimony of Gabrielle Peters before the Standing Senate Committee on Legal and Constitutional Affairs, as delivered by Spring Hawes. February 3, 2021. Transcript at <https://sencanada.ca/en/Content/Sen/Committee/432/LCJC/55130-e> [↑](#footnote-ref-15)
16. Testimony of Sarah Jama before the Standing Senate Committee on Legal and Constitutional Affairs. February 1, 2021. Transcript at <https://www.sencanada.ca/en/Content/Sen/Committee/432/LCJC/10ev-55128-e> [↑](#footnote-ref-16)
17. Testimony of Heidi Janz before the Standing Senate Committee on Legal and Constitutional Affairs. February 1, 2021. Transcript at <https://www.sencanada.ca/en/Content/Sen/Committee/432/LCJC/10ev-55128-e> [↑](#footnote-ref-17)