

**C A N A D A**

**PROVINCE OF QUÉBEC  
DISTRICT OF TROIS-RIVIÈRES**

**NO: 400-17-002642-110**

**SUPERIOR COURT  
(Civil Division)**

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**GINETTE LEBLANC**

Plaintiff

c.

**ATTORNEY GENERAL OF CANADA**

Defendant

**ATTORNEY GENERAL OF QUEBEC**

Mis-en-cause

**CHRISTIAN LEGAL FELLOWSHIP/ALLIANCE  
DES CHRÉTIENS EN DROIT**

Intervener

**EUTHANASIA PREVENTION COALITION**

Intervener

**VIVRE DANS LA DIGNITÉ**

Intervener

**ASSOCIATION QUÉBÉCOISE POUR LE DROIT  
DE MOURIR DANS LA DIGNITÉ**

Intervener

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**AFFIDAVIT OF CATHERINE FRAZEE**

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I undersigned, Catherine Frazee, domiciled and residing at \_\_\_\_\_, Nova Scotia make oath and say:

1. I currently hold the position of Professor Emerita at Ryerson University, School of Disability Studies.

2. I have been retained by the Attorney General of Canada to provide my expert opinion on various questions in my field of expertise, as set out in this report.
3. I am the sole author of this affidavit and am responsible for the opinions expressed throughout.
4. Some of the documents attached to this affidavit are authored or contributed to by myself and are based upon my own research and experience. Where I refer to these materials I adopt them as part of my expert opinion report filed in this proceeding.
5. Some of the documents referenced and attached to this affidavit are not authored or contributed to by myself. Where I am not the author or contributor, I have reviewed the material and consider the conclusions drawn to be authoritative in my area of expertise, reasonable and in accordance with my own experience and work in this field.
6. I am aware I have a duty to assist the court and that I may not advocate for any party. I have prepared this affidavit in conformity with my duty to the court.

### **Qualification and Expertise**

7. My *curriculum vitae* is attached to this affidavit as **Exhibit A**.
8. I currently hold the position of Professor Emerita at Ryerson University, School of Disability Studies. Prior to my retirement in 2010, I was a Professor of Distinction in the School of Disability Studies and Co-Director of the Ryerson-RBC Institute for Disability Studies Research and Education.
9. From 1989 to 1992, I served as Chief Commissioner of the Ontario Human Rights Commission, a full-time position of senior executive responsibility for the enforcement and promotion of the Ontario Human Rights Code. This role involved oversight of the investigation, mediation and disposition of all complaints of discrimination filed under the Code, as well as leadership for all of the Commission's mandated policy, systemic and

public education initiatives. Prior to this appointment, I had served for four years as a part-time Commissioner for Human Rights in Ontario.

10. I have served in a voluntary capacity as Director, Task Force Chair, advisor and active contributor to various national and local civil society organizations promoting the equality and full citizenship of people with disabilities in Canada. These organizations include the Canadian Association for Community Living, the Council of Canadians with Disabilities, the Disabled Women's Network of Canada and the Center for Independent Living in Toronto.
11. I have lectured and taught extensively across Canada on subjects related to the history, rights claims, culture and precarious citizenship of disabled people. As Professor of Distinction at Ryerson University, I designed and taught courses introducing undergraduate students to the social roots and impacts of disability discrimination, exclusion and marginalization. I designed and taught courses for the School of Disability Studies on Canadian Disability History, Social Policy and Human Rights. By cross-appointment to the Department of Philosophy, I taught Ethics and Disability, a course that specifically addressed the philosophical orientations to disability underpinning contemporary debates about assistance in dying.
12. I was the Bertha Wilson Visiting Scholar in Human Rights Law at Dalhousie University's Faculty of Law in 2000.
13. From 2000 through 2003, I served as a faculty member for the National Judicial Institute, participating in the design and delivery of judicial education programmes in social context awareness.
14. I have provided expert opinion testimony on critical disability analysis and social context theory before the Federal Court of Canada in the case of *Chesters v. Canada (Minister of Citizenship and Immigration)*, 2002 FCT 727 and on disability and accessibility before the

Canadian Human Rights Tribunal in the case of *Hughes, James Peter v. Election Canada*, 2010 CHRT 4.

15. I provided expert opinion evidence to the Supreme Court of British Columbia regarding the risks that assisted dying poses for people with disabilities in *Carter v. Canada (Attorney General)*, 2012 BCSC 886.
16. I have also served as an expert on equality, human rights, disability issues and disability disadvantage at Boards of Inquiry appointed under the Ontario Human Rights Code: *Elliott v. Epp Centres Inc.* (1993), 13 L.W. 1318-029; *Quesnel v. Eidt* (1995), unreported; *Lewis v. York Region Board of Education*, [1996] O.H.R.B.I.D. No. 25; *Brock (Litigation Guardian) v. Tarrant Film Factory Ltd.*, [2000] O.H.R.B.I.D. No. 5; *Turnbull v. Famous Players Inc.*, [2001] O.H.R.B.I.D. No. 20; and *Turnbull v. Famous Players Inc.*, [2003] O.H.R.T.D. No. 10, as well as before the Supreme Court of Ontario: *Poynter v. St. Vincent Hospital*, 1988 (unreported).
17. I have spinal muscular atrophy, a neurological condition that is progressive and irreversible. My physical impairments as a result of this condition are significant. I rely upon extensive technological support to function in the world: a highly customized motorized wheelchair, a ventilator, suction machine, patient lifting device, and voice recognition software for computer access. I am dependent upon 24-hour personal assistance for the most intimate details of my self-care: bathing, toileting, dressing, body positioning and feeding.

## **Mandate**

18. The Attorney General of Canada has asked me to address the following issues:
  - a) The experience of people with disabilities in Canadian society broadly and in the medical system in particular;
  - b) The principle of autonomy in relation to the disability experience;

- c) The potential impacts of assisted suicide on people with disabilities.
19. I have reviewed the following documents in forming my opinion: a translated copy of the Plaintiff's claim and affidavit and a translated copy of the affidavit of Prof. Daniel Weinstock.

## **Analysis**

### **I. The experience of people with disabilities in Canada, particularly in the medical system**

#### **i. Relevant Research and Policy**

20. In this section of my affidavit, I shall present a brief annotation of relevant benchmarks and observations from my own professional experience that illuminate the social context within which people with disabilities experience medical services and care in Canada.
21. Between 1999 and 2002, I was part of a team of three researchers investigating the legal and policy frameworks affecting the health and well-being of disabled women in Canada. This project, funded by the National Network on Environments and Women's Health, revealed a persistent pattern:
- "Systems, programmes, policies and laws presumably put in place to assist and promote the well-being of people with disabilities too often have the opposite effect, oppressing and disenfranchising the targeted population and eroding the dignity of women with disabilities."
22. The project's final report underscored the extent to which a lack of regard for the rights and dignity of people with disabilities has been evident in clinical encounters within the healthcare system. Citing the Supreme Court of Canada's articulation of a long history of exclusion and marginalization of disabled people in *Eldridge v. British Columbia (Attorney General)*, [1997] 3 S.C.R. 624 the report highlighted policies and clinical decisions that:

"have harmed and disadvantaged people with disabilities. Treatment has been denied or not offered, either because it was not physically accessible, or because the person concerned was judged 'unable to benefit' or the circumstances of his or her life were considered to be such that they did not warrant aggressive intervention."

23. In 2007/2008, I joined a team of investigators engaged in a study of end-of-life care for people who experience socially-constructed vulnerability. Funded for five years by the Canadian Institute for Health Research, the [Vulnerable Persons and End-Of-Life New Emerging Team \(VP-NET\)](#) brought an interdisciplinary perspective to policy and practice issues related to disability and end-of-life. In my specific role in the "Reclaiming Language" project, I explored how values, perceptions and framings of the experience of disability are embedded in the language commonly featured in end-of-life discourse.
24. Of paramount concern for the VP-NET team was the negotiation of deep and long-standing tensions between persons with disabilities and health care professionals. The team's work was premised on a shared understanding that:

The belief that disability and illness inevitably lead to a lower quality of life is widespread both among people working in the healthcare system and people in the general population. This belief often leads to a lack of healthcare options because the idea of trying to prolong a life that is assumed to be unpleasant seems futile. However, this belief is not based on the experiences of people with disabilities, whose perspectives are rarely incorporated into healthcare systems or decision making.

25. A plain language synthesis of the most salient conclusions of this work can be found on the Vulnerable Persons and End-Of-Life website, under the heading "[Media and Societal Perceptions of Disability](#)". In particular, this document, attached to this affidavit as **Exhibit B**, reports that:

Policies and programs are born out of a popular environment. Images in the media reinforce a negative perception of life with disability that helps to justify euthanasia or withdrawal of life sustaining or curative therapies for people with disabilities.... Public and media discussion is dominated by the concept of 'the right to die with dignity' which reinforces the belief that "some forms of living are too burdensome, too hopeless, or too unaesthetic to merit support." This is

further supported by an increasing intolerance for human limitation and glorification of the perfect body throughout the media.

*(Internal citation is from Gill, Carol J. "Disability, Constructed Vulnerability, and Socially Conscious Palliative Care" in Journal of Palliative Care. Toronto: Autumn 2006. Vol. 22, Iss. 3, p. 183(8). This article is attached to this affidavit as **Exhibit C.**)*

26. For nearly two decades, I have been associated with the Council of Canadians with Disabilities (CCD), Canada's national, cross-disability human rights organization, working for an accessible and inclusive Canada. Similarly, I have been associated as a Director and Task Force chair for the Canadian Association for Community Living (CACL) for over 10 years. CACL is a national federation of associations assisting people with intellectual disabilities and their families working to advance inclusion in Canadian society.
27. In these roles, I have acquired direct knowledge of how disabled Canadians and members of the Community Living movement have engaged in serious reflection, research and debate in formulating policy positions with respect to the legalization of assisted suicide.
28. In November 1994, the CACL strongly urged the Senate Committee on Euthanasia not to legalize euthanasia or physician-assisted suicide. A copy of the CACL's submission to the Senate Committee is attached to this affidavit as **Exhibit D**. In this submission, the CACL argued that "the use of substitute decision-making through guardianship and determination of competence would place people who have an intellectual disability at significant risk of being euthanized without their consent".
29. CACL reasoned that "in a society which legitimizes the practice of euthanasia or assisted suicide, people who are perceived to be less valuable and their families will face increasing pressure and reinforcing messages regarding their value to society. The result will be that many will 'choose' assisted suicide based on their devalued sense of themselves." The submission went on to identify broader social impacts from a permissive approach to physician-assisted dying: "... selected active euthanasia will be seen as a social alternative to the provision of supports, services and the recognition of human rights."

30. In 2010, representatives of CACL appeared before the House of Commons Committee on Palliative and Compassionate Care. In their submission, attached to this affidavit as **Exhibit E**, they detailed the Association's deep concern about the extent to which "quality-of-life" assessments distort the advice of medical professionals and place the lives of people with intellectual disabilities in "immediate peril". They reported that families:

... are told by medical professionals and experts that their family member's life is in immediate peril, that efforts to support him or her are futile, that the family should leave their loved one be and let him or her die with dignity. Families, under pressure, often sleep-deprived and in the throes of emotional trauma rely on their trusted doctors to provide them with unbiased information..... Yet, life-and-death medical decisions are being made on a particular perspective of quality of life.

The report cites numerous well-documented examples to illustrate a pattern of "continued and active devaluation of people with disabilities – particularly those with complex medical needs and significant support needs – in our medical systems today". I have reviewed this report and adopt it and its conclusions as a part of my opinion.

31. In response to the BC Supreme Court decision in *Carter v British Columbia (Attorney General)*, CACL issued a [press release](#) decrying the court's decision to strike down *Criminal Code* sanctions against assisting suicide. The statement, attached to this affidavit as **Exhibit F**, speaks of "the wider impact on people with intellectual disabilities", concluding:

our concern ... is that rather than advancing equality rights for Canadians with disabilities, this ruling will have quite the opposite effect. We fear that by embedding in Canadian law the message that some forms of human life are less worth living, the historic disadvantages faced by Canadians with disabilities that the equality rights provisions of the Canadian Charter of Human Rights and Freedoms were to address, will only be more deeply entrenched.

32. In August of 2012, the Values and Ethics Task Force of the Canadian Association for Community Living, of which I am a member, met to discuss the implications of the Carter decision and to develop a more fulsome articulation of how the equality interests of people

with disabilities are undermined by the striking down of s 241(b) of the *Criminal Code*. As a result of these deliberations, a comprehensive resolution reaffirming CACL's opposition to assisted suicide will be presented to a meeting of the full membership in September of this year.

33. In 1996, the CCD went on record as opposing "any government action to decriminalize assisted suicide because of the serious potential for abuse and the negative image of people with disabilities that would be produced if people with disabilities are killed with state sanction". A copy of the resolution then adopted by the CCD is attached to this affidavit as **Exhibit G**. I was involved in drafting this resolution and adopt it and its conclusions as part of my opinion.
34. In 2003, with support of the Canadian Bar Association, CCD commissioned a detailed review of the "issues involved in the legalization of physician-assisted death". I have reviewed this [report](#) authored by Mr. Orville Endicott and adopt it and its conclusions as a part of my opinion. This report, which is attached to this affidavit as **Exhibit H**, reasoned that for people with disabilities "personal autonomy" may not be a reliable safeguard because of the extent to which their lives are socially devalued. Acknowledging that "outside influences on the decision to consent to the termination of one's own life are rarely so blatant as to be easily identified as 'coercion'", the report emphasized that such influences are "nevertheless very real and powerful".
35. The 80-page report concluded:

"... there are serious risks to persons with disabilities in societies where assisted death is regarded as a solution to the suffering and anxiety that many experience as they near the end of their lives. For most people in that circumstance, assisted death may be regarded as "merciful" because it relieves them of the physical and mental ordeal they would otherwise have to endure. For people with disabilities, however, the "mercy" is often seen in terms of ending a life that is perceived by others to be devoid of value because of the individual's disability, rather than being intolerable for the individual because of pain and suffering. Even in Canada, where the law officially continues to uphold the traditional uncompromising respect for human life, safeguards against resorting to assisted death are seriously wanting. Until it can be

convincingly demonstrated that all Canadians enjoy full equality and security of the person, regardless of disability, as guaranteed by the *Charter of Rights and Freedoms*, then any steps toward legalized assistance in dying should be resisted."

36. CCD's position was strongly reaffirmed in June 2010, when council representatives presented to the federal House of Commons Committee on Palliative and Compassionate Care. The full text of this [brief](#) is attached to this affidavit as **Exhibit I**. I have reviewed this brief and adopt it as a part of my opinion.
  
37. In that brief, following 15 years of continued analysis and consideration of this pressing social policy issue, CCD concluded that legalizing assisted suicide "would violate our principles supporting equal, dignified and self-determining lives for people with disabilities".
  
38. In a press release detailing CCD's submission to the Committee on Palliative and Compassionate Care, attached to this affidavit as **Exhibit J**, Rhonda Wiebe, Chair of CCD's Ending of Life Ethics Committee, spoke of "the insidious stereotypes that bring harm to people with disabilities". She recounted the experience of a now-deceased colleague who had gone to hospital to be treated for pneumonia:

[Mike] expected treatment to cure his illness. However, his doctors offered to make him comfortable while nature took its course. Members of the disability community had to advocate on his behalf to get him the treatment he needed."
  
39. In my 30-odd years of research, study and human rights work, I have encountered many, many such narratives that underscore the precarious hold that disabled citizens have upon life itself, when those with gate-keeping authority in medical and other professions permit their own subjective assessments of the value of life with significant impairment to shape judgment and advice. Although to my knowledge there are no definitive studies that offer statistical tracking of such incidents, I have no doubt about the frequency of their occurrence and the authenticity of their reporting. It is my opinion that narrative accounts such as these chronicle a recurring pattern of socially constructed vulnerability to death-hastening policies or practices.

40. The following account, for example, articulated by a former colleague, was reported in an article authored by one of her husband's consulting neurologists. This article, attached to this affidavit **as Exhibit K**, offers a vivid recounting of the extraordinary strength that must be mustered to resist the influence of those whose framings of suffering, quality of life, and compassion conform to prevailing presuppositions about disability.
41. Mr. Justice Sam Filer, first diagnosed with ALS in 1987, went into respiratory failure while in hospital in January, 1989. His wife Toni Silberman describes what followed:

The doctors would not allow me into his bedroom because they, in their mercy, didn't want me to watch him die. I thank them for that. What I don't thank them for is their reluctance to proffer, except under extreme duress, alternatives to his death.

Six attending physicians encircled me, offering assurance that it would be inhumane to not let him die with dignity; that his care would become financially ruinous; that I had an infant at home to whom I owed my devotion; that there is, not could be but is, no quality of life once ventilated; and that I had ten minutes in which to make my decision. [Sam and I] had discussed ventilation as an option – but those discussions were academic and distant at the time. The reality was far more ominous and frightening.

Being well trained as a psychologist, I thanked the doctors for sharing their feelings with me, and suggested that their expressed concerns were our responsibility, and keeping Sam alive was theirs. In retrospect, I recognize that the doctors, based on their experiences, were making medically and socially approved assumptions. But those assumptions were, in our case, the wrong ones. Only two of the six doctors, to their credit, had the courtesy to say that although they disagreed with the decision, they would do everything possible to ensure that the procedure would be a successful one. They did, and it was. Sam's new life began when he left the I.C.U.

42. Justice Filer continued to work as an Ontario Superior Court Judge until his retirement in 2004. Defying all prognostications, he lived until 2007.

**ii. Summary and opinion with respect to the social position of disabled people and, in particular, their relations with institutions of contemporary medicine**

43. On the basis of my study of and engagements with Canada's disability rights movement, especially as highlighted in paragraphs 21 through 42, it is my opinion that a nuanced understanding of the social experience of people with disabilities reveals subtle patterns of harm and disadvantage that defy easy detection and measure.
44. Disabled people have a distinct experience. We are perceived as less fortunate than nondisabled people and assigned a diminished status in everyday life – these perceptions and status shape our experience, both when we are lively and autonomous and when we are fragile and vulnerable.
45. Disability rights advocates have for decades fought against negative stereotypes, discriminatory barriers and persistent cultural devaluation in the effort to achieve equality. Discrimination on the basis of disability – both direct and systemic – is pervasive and persistent. As acknowledged by the Supreme Court of Canada in the Eldridge decision:

It is an unfortunate truth that the history of disabled persons in Canada is largely one of exclusion and marginalization. Persons with disabilities have too often been excluded from the labour force, denied access to opportunities for social interaction and advancement, subjected to invidious stereotyping and relegated to institutions...

46. Judgments about the particular conditions of disabled people's lives are overwhelmingly dominated by anxiety, prejudice and stigma. Disabled people's functional limitations and reliance upon human and technological supports are both pitied and feared. Conditions that become routine aspects of life for disabled people – such as reliance upon ventilators or feeding tubes, or the need for human assistance with intimate personal care, or bodily difficulties such as drooling or incontinence or the inability to communicate through conventional means – give rise to deep and persistent unease among people immersed in the values of an ableist culture. For this reason, the lives of disabled people are widely held to be tragic. As noted by Orville Endicott in the report attached to this affidavit as Exhibit H:

Society in general attributes negative characteristics to persons with disabilities. Their lives are regarded as having less value, both to themselves

and to the society around them, than the lives of individuals who do not have disabilities."

47. There is also a considerable body of research demonstrating that disabled persons are victims of violence at rates significantly higher than those experienced by non-disabled persons.
48. As noted in paragraphs 21 through 42, disabled people have had an ambivalent and troubled relationship with institutions of healthcare and medicine. Many healthcare professionals tend, like others in positions of economic and social power and authority, to regard the quality of life of disabled people as unacceptably poor when compared with their own.
49. A consistent thread running through narratives of disabled peoples' encounters with medical professionals suggests that disabled patients have a qualitatively different experience from the acutely ill – but otherwise non-disabled – patient. Recurring accounts from Canadians with disabilities and their family members report situations of denial or withdrawal of life-saving treatment, presumptive steering toward Do Not Resuscitate orders and/or premature surrender to 'comfort care'. At the heart of these accounts are fundamental assumptions about quality of life. As noted by Orville Endicott in the report attached to this affidavit as Exhibit H:

Do Not Resuscitate orders are often entered in patient charts, not because an attempt to resuscitate the person would be futile, but because the individual's life is negatively valued because of disability.

50. Research studies, attached to this affidavit as **Exhibit L**, indicate that physicians in particular and medical professionals in general, consistently and dramatically underestimate quality of life for their disabled patients, as compared to the assessments which those same individuals make of their own lives.
51. Aside from quality-of-life assumptions, there are other significant challenges that people with disabilities face within the medical system. Many examination and treatment facilities are not accessible to people with various impairments; few medical facilities – even post-

Eldridge – offer ready access to sign language interpretation; few healthcare professionals have had any exposure to a disability perspective on fundamental questions of ethics and practice.

## II. The principle of autonomy in relation to the disability experience

52. As demonstrated in the Reclaiming Language project referred to in paragraphs 23-25 of this report, language is a powerful tool in the ordering of human relations. Words such as dignity, autonomy and choice, like vulnerability and compassion, can be distorted, and their meanings effectively reversed. In the language used to support demands for physician-assisted suicide, we have many examples of this kind of inversion.

53. The concepts of dignity, autonomy, and choice have been clarion calls of the disability rights movement in Canada and around the world. These concepts have served the movement well, as respect for the autonomy of disabled people is universally recognized as a precondition for any claim to substantive equality. The critical value of autonomy is affirmed as follows in paragraph n of the preamble to the *United Nations Convention on the Rights of Persons with Disabilities*, attached to this affidavit as **Exhibit M**:

Recognizing the importance for persons with disabilities of their individual autonomy and independence, including the freedom to make their own choices...

54. Proponents of suicide assistance argue that the decision to choose the precise time and method of one's own death is the ultimate exercise of personal autonomy. However, organizations mandated to advance the equality rights of citizens with disabilities in Canada and the US, including CCD and CACL, overwhelmingly reject this argument, standing together in opposition to any decriminalization of suicide assistance. For example, as noted in paragraph 35 of this affidavit, the CCD has concluded that legalizing assisted suicide "would *violate our principles* supporting equal, dignified and *self-determining* lives for people with disabilities". [Emphasis added.]

55. At first glance, there may appear to be a problematic inconsistency in the positions taken by CCD and CACL in relation to the principle of autonomy. On the one hand, respect for autonomy and self-determination are cornerstone principles of the disability rights movement, and embraced as such in the core principles of both of these organizations. On the other hand, both organisations firmly oppose any framing of a request for assistance in committing suicide as an exercise of personal autonomy.
56. On closer examination, however, what may appear at first as a selective disregard for the principle of autonomy, is, in my opinion, quite the opposite. The accounts and positions developed by Canada's leading disability rights organizations in fact reflect an unqualified commitment to a robust and nuanced account of autonomy that is entirely consistent with fundamental principles of equality.
57. In this section of the report, I shall attempt to delineate the principal features of this account of autonomy, as I have come to understand it through my involvement with the research and policy enterprises highlighted in paragraphs 21 through 42.
58. My observations will be organized under the following headings:
- Autonomy must not be compromised;
  - Autonomy must not be confused with sovereignty;
  - Autonomy must not be invoked in support of wrongly construed rights;
  - Autonomy must not be invoked *simpliciter* in ways that undermine, rather than protect, human dignity and equality.

**a) Autonomy Must Not Be Compromised**

59. It is, for all practical purposes, impossible to isolate a request for assistance to end one's life from the context within which such a request is made. For this reason, within a social order that widely perceives disabled people's lives and lifestyles to be of diminished value, the availability of medical assistance to terminate life upon demand places some people at risk of making a "choice" that does not reflect their true, autonomous desires.

60. This is of course not to say that disabled people are incapable of or universally precluded from exercising true autonomy, or that there are no circumstances under which a competent adult could choose autonomously to be assisted to die, rather than to permit a terminal, disabling condition to run its course. It is, however, an argument that affirms the inevitability that some persons will be vulnerable to internalizing pervasive messages of social fear and shame, and find themselves effectively backed into a request for suicide assistance as their only "reasonable" or "honourable" option.
61. Such requests, according to policy positions articulated by the CCD and its American counterpart, the National Council of Disability, in a position paper dated March 24, 1997, would decidedly **not** be autonomous in nature. A copy of this [position paper](#) is attached to this affidavit as **Exhibit N**.
62. Autonomous choices cannot be assured in the context of the social and material deprivations of disabled person's lives, and the immense social and cultural pressures that erode disabled people's sense of belonging and equal human worth.
63. As long as people with disabilities are disenfranchised and made to feel that they are burdens to their society and to those who support them in their community, there can be no assurance that assisted suicide is pursued as a free choice. There can be no assurance that such requests are indeed expressions of true personal autonomy as long as people with disabilities are overwhelmingly denied adequate healthcare, housing, transportation, personal support services, assistive technology, education, employment, and community access.
64. Disability turns many social relations upside down. Whereas nondisabled people conceive of assisted suicide as a method of preserving autonomy in the face of debilitating illness and decline, many disabled people will experience the possibility of an assisted death as one that undermines autonomy, depending upon their place in social hierarchies of power.

65. Moreover, protocols aimed at safeguarding vulnerable populations from the hostile influence of socially embedded disability prejudice are at best, naïve in their confidence that autonomy can be protected and assured. It is impossible to conceive of any procedural intervention so astute as to detect, unfailingly, the influence of stigma, shame, guilt or prejudice in an end-of-life decision-making process. Such influences by their very nature are subtle, insidious and pervasive. Their effects are felt over the course of a lifetime, long before the triggering moment of a request for suicide assistance. And they are enacted in the most informal and seemingly inconsequential everyday encounters, well beyond the reach of even the most rigorous screening procedure.

**b) Autonomy Must Not Be Confused with Sovereignty**

66. Disability rights organizations in Canada have given critical attention to the unexamined proposition that deciding to end one's own life is the ultimate expression of autonomy. Increasingly, their policy discussions on the subject of assisted suicide reject the suggestion that suicide is an expression of autonomy, freedom or liberty.

67. Instead, suicide is, by its nature, a matter of an individual's sovereignty over their body – a matter of each person's sovereignty over their existence, quite distinct from a freedom, liberty or expression of autonomy that is accorded the protection of law.

68. Suicide is not so much an expression of autonomy, as it is a place that the law cannot touch. Suicide can be seen as an act that is an expression of 'sovereignty' – a purely private act, outside of the domain of rights and freedoms as these concepts are understood in the context of the assisted suicide debate.

**c) Autonomy Must Not Be Invoked in Support of Wrongly Construed Rights**

69. Similarly, disability rights organizations have challenged the notion that suicide is a "right" enjoyed by people who are physically capable of ending their own lives. They assert that no specific entitlement to commit suicide can be gleaned from its removal

from the *Criminal Code* in 1972. The decriminalization of suicide does not amount to the establishment of a so-called "right to die".

70. Suicide cannot be construed as a right to which a claim for equality can be made. Death is not a right. Neither is dementia, necrosis, myopia, infection, or any other pathology or biological process.
71. Many conditions, capacities and choices are called "rights" in modern libertarian discourse, but each of these so called "rights" must be subject to careful scrutiny in a constitutional democracy committed to pluralism and diversity.
72. Invoking the principle of autonomy to claim a "right" to a particular method of suicide, gravely distorts the meaning of autonomy for persons with disabilities and trivializes hard-fought-for rights secured under the *Charter's* guarantee of equality. Autonomy is inherently a life-affirming value, a vital thread running through myriad acts of self-creation. Suicide stands apart from this tapestry as a single act of self-destruction.
73. Philosophically, there is support for this position in the argument that autonomy cannot justify actions which remove or terminate the future exercise of autonomy. Since the publication of John Stuart Mill's essay "On Liberty" in 1869, there is a well-established line of ethical thought that such actions as committing suicide or selling oneself into slavery should be prevented in order to avoid precluding the further exercise of freedom. More recently, Charles Taylor's articulation of the notion of 'radical re-evaluation' gives rise to affirmations that autonomy can be infringed to preserve the possibility that our views may radically change in the future. To the extent that assisted suicide forecloses the possibility for radical re-evaluation of one's threshold for life worth living, its prohibition can be ethically justified.

**d) Autonomy must not be invoked *simpliciter*, in ways that undermine, rather than protect, human dignity and equality**

74. Disability prejudice and stereotype are embedded in the discourse around physician assisted suicide. Loss of control of bodily fluids is repeatedly and emphatically represented as an assault of suffering and indignity, such as to render life no longer worth living. Loss of mobility and diminished capacity for independent self-care are consistently described as a stripping away of dignity. Despair and surrender are uncritically accepted as the only possible response to a hopeless predicament – a predicament invariably associated with social shame. Yet the link between dignity and independent physical self-care is not absolute.
75. The reasons most frequently given for people wanting to avail themselves of assisted suicide are related not to pain or physical suffering, but to anxieties about loss of independence – in particular, loss of independent capacity to bathe, dress, and go to the bathroom. Such anxieties are serious and worthy of responses that are sensitive and attuned to the circumstances of each individual, but they do not constitute a social imperative sufficiently compelling to warrant a legal measure that could imperil the life of another.
76. When we accept uncritically that reliance upon assistance with bodily functions diminishes dignity to such an extent that life is no longer worth living, we trivialize the true meaning of human dignity and denigrate the lives of people who rely upon others for intimate physical support in their daily lives. Only the most simplistic and superficial formulation of autonomy can seriously posit death as a proportionate response to anxieties surrounding bodily functions.

**III. The potential impacts of assisted suicide on people with disabilities**

77. Disability rights organizations such as the CCD and the National Council of Disability in the US have struggled with the policy implications of physician-assisted suicide for

decades. The issue poses an excruciatingly difficult question, because the effect of leaving intact existing criminal prohibitions against assisted suicide is to frustrate the deep desire of some individuals with disabilities, such as the petitioner in this case. This position is not taken lightly or without considerable regard for Ms. LeBlanc and others in similar circumstances.

78. However, the availability of physician-assisted suicide would put many disabled people at risk. In this final section of my report, I shall elaborate upon the nature of that risk, detailing two distinct categories of harm that are not only likely but in my opinion inevitable, should paragraph 241(b) of the *Criminal Code* be struck down.

- Direct and immediate harm: Some people with disabilities will be unjustly denied the opportunity to live life to its natural end; and
- Systemic and symbolic harm: Socially and culturally embedded patterns of disability disadvantage, prejudice and exclusion will be perpetuated and reinforced.

**i. Direct and Immediate Harm**

79. As reported by Orville Endicott in the report attached to this affidavit as Exhibit H:

There is a considerable body of public opinion in Canada and elsewhere that ending the life of a person with a disability is much less blameworthy than killing a person who does not have a disability. Often the killing of a person with a disability is characterized as "mercy killing" regardless of whether the individual was experiencing severe pain.

... If the movement to legalize physician-assisted death gains momentum, there is every reason to expect that a disproportionate number of those who will be "assisted"... will be persons with disabilities.

80. Although early studies in jurisdictions which permit physician-assisted suicide have not pointed to a disproportionate number of people with disabilities receiving such "assistance", it is entirely possible that longer-term experience will reveal otherwise. Whether or not this kind of empirical data ultimately supports Endicott's assertion, there are equally significant, though far less easily measurable ways in which people with

disabilities may have pursued assisted suicide for reasons that are rooted in social disadvantage rather than free and autonomous choice. In other words, it is possible that people with disabilities have been and will continue to be disproportionately influenced by discriminatory factors in their end-of-life decision-making.

81. The direct and immediate harm therefore occasioned by the availability of suicide assistance is perhaps not that too many people with disabilities will choose to die, but that too many of those who do make this choice will do so because of injustice, rather than autonomy.
82. I know of no way accurately to measure the extent to which a lifetime of exclusion, marginalization and material and social deprivation erodes the will to live. Nor can I point to studies that document how exposure to distorted representations of disability determines the intensity of one's refusal to embrace disablement at life's end. I cannot precisely quantify how an absence of regard in homes, places of work and communities undermines our authority and confidence when we are thrust into the turbulent waters of end-of-life decision-making. It is decidedly my opinion, however, that such factors have cumulative effect, and that such effect will at times diminish one's resilience to pain, adversity and misfortune, dampen one's creativity and incline one toward hasty surrender.
83. Many who have contemplated suicide, myself included, experience a change of circumstances or heart, in time growing through a personal but radical rethinking of the value of life in the particular form it has taken. The availability of physician-assisted suicide may cause direct and immediate harm to those who are enabled to act on their first impulse, and thereby denied this opportunity for fundamental rethinking.
84. Most people who express suicidal wishes are strongly supported to resist self-destructive impulses. Regardless of protocols put in place to protect the vulnerable, there can be no certainty that persons whose quality of life has been judged as unacceptable will receive the full benefit of such intervention. Hence, another potential for direct and immediate

harm, occurring well "below the radar" of procedural safeguards and monitoring mechanisms.

85. As well, there is good reason for concern that the popular and pervasive cultural scripts that narrate disabled lives as heroic will be transformed to hold out an elusive promise of esteem, for persons willing to sacrifice their own lives so that others will be spared the burden of caring for them. As Diane Coleman has written:

For individuals who internalize the social oppression that declares severe disability to be undignified, the legalization of assisted suicide may convey the message that suicide is the best way to reclaim their dignity. It may even convey the message that suicide is the most honourable way to make one last contribution to a society that increasingly operates from a "lifeboat" mentality, a mentality that tells the disenfranchised and despised to get out of the way, without ever seriously questioning the decisions and motives of the policy-makers who shape the culture we live in.

*Citation:* Chapter 10, "Not Dead Yet" by Diane Coleman, President of Not Dead Yet in [The Case Against Assisted Suicide - For the Right to End-of-Life Care](#), edited by Kathleen Foley, M.D., and Herbert Hendin, M.D., John Hopkins University Press, 2002 (Attached to this affidavit as **Exhibit O**)

86. Moreover, there already exists an ambivalent relationship between the medical professions and people with disabilities. These relationships would not be made less difficult, less ambivalent or less troubled if the professionals entrusted with our care could legally terminate our lives, even upon our own direction. Disabled people might become less, rather than more, likely to be forthright with their physicians about their fears and desires.
87. Perhaps most worrisome, in the context of a more permissive approach to death hastening for people with impairments, it is conceivable that some physicians and family members may feel less inhibited from covert (and unlawful) practices of involuntary euthanasia – an area where procedural safeguards are of no effect.
88. Taking all of these factors into account, I must disagree with the conclusion of Professor Daniel Weinstock, as expressed in his affidavit, dated May 8, 2012. Professor Weinstock acknowledges that "real risks exist" but that they are "insufficient" to "justify" denial of

access to suicide assistance. In my view, given that real risks of discriminatory influence do exist, and that regulatory protocols put in place to minimize such risks cannot be stripped of all human subjectivity, and that anxieties about disability take hold well below the level of liberal consciousness, there is at least a reasonable possibility of harm to vulnerable persons.

89. I would emphasize that this reasoning does not rely upon the spectre of an all-out genocide or eugenic slippery slope. Such a catastrophic outcome may or may not be the ultimate endpoint that begins with socially sanctioned suicide assistance, but for the purpose of the present discussion, it is not necessary to settle that debate.
90. Instead, in my opinion, if even one person dies prematurely for reasons that accord with a compromised autonomy, then limiting the privilege to choose the precise time and manner of one's death, is justified.

**ii. Systemic and Symbolic Harm**

91. Notwithstanding the seriousness of the potential for direct and immediate harm where suicide assistance is pursued in the absence of true autonomy, the striking down of section 241(b) of the *Criminal Code* would have other more far-reaching and profound effects.
92. As acknowledged by Chief Justice Dickson in *R. v. Keegstra*, [1990] 3 SCR 697:

A person's sense of human dignity and belonging to the community at large is closely linked to the concern and respect accorded the groups to which he or she belongs.
93. The removal of long-standing Criminal Code protections contained in section 241(b) would constitute a highly visible and authoritative endorsement of a particular set of ideas and values. In my opinion, and for the reasons detailed in this report, those ideas and values demonstrate a clear lack of respect for the life experience of disabled persons.

94. The ideas and values that find expression in support for physician-assisted suicide cluster around a basic acceptance that loss of control over one's body at end-of-life constitutes a catastrophic and irreversible violation of human dignity, serious enough to warrant taking direct measures to end one's own life. Mobility, speech, physical independence and control of bodily functions are highly prized capacities, considered by many to be requisite conditions for the enjoyment of privacy, autonomy and well-being.
95. Yet across this country and around the world, people with disabilities negotiate physical dependence and functional limitation as routine dimensions of everyday life. Those with access to adequate and appropriate supports live with their dignity intact and their privacy, autonomy and well-being undiminished. Most do not perceive themselves to be "suffering" by virtue of their impairments. The ideas and values that find expression in their lives cluster more around a perennial quest for recognition, respect and equality, rather than avoidance, pity and shame.
96. I would emphasize here that there is nothing inherently harmful or destructive about assigning a high value to physical fitness and capacity. Nor is it problematic to recognize and honour the grief that flows from serious losses in this domain. What is harmful, and ultimately destructive of efforts to nurture a just and pluralistic society, is to denigrate bodily incapacity to such an extent that it becomes a sufficient condition for assisted suicide.
97. Typically, petitions for assistance in dying rely upon a logic that equates bodily incapacity with indignity. While such assertions are deeply personal and no doubt subjectively authentic at the point in time when they are uttered, they cannot be teased apart from the milieu of negative ideas and values about disability in which they took root. To craft a legal right to die in response to a petition of this nature is to elevate its flawed core assertion to the status of social policy. It is impossible to grant a request for suicide assistance while rejecting the underpinning logic that bodily incapacity is shameful and undignified.

98. In other words, when the state sanctions measures to hasten death in response to a claim that certain levels of physical impairment are so undignified and degrading as to render life intolerable, long-standing patterns of disabled people's devaluation are affirmed and reproduced. Others will become more – rather than less – inclined to take up and embrace cultural taboos about disability. In this way, a diffuse yet pervasive social harm is inflicted.
99. This harm is complex and multifaceted. It is carried not only in the logic of petitions and legal arguments, but in the language with which the debate is framed. For example, descriptions of petitioners' circumstances frequently draw from an ableist vocabulary that frames adaptive technologies such as wheelchairs, voice synthesizers, ventilators and feeding tubes not as marvels of modern invention, but rather as symbols of degradation and confinement. Similarly, acts of caregiving and personal support are described in language that strips both the care provider and the care recipient of their humanity, and erases any recognition of the delicate relational chemistry of such arrangements. Assertions such as Ms. LeBlanc's painful claim that "I will become a prisoner of my own body and lose all autonomy" or Gloria Carter's assertion that "What I fear is a death that negates, as opposed to concludes, my life" become sound-bites in the court of public opinion where prejudice and fears about disability abound.
100. The offer of suicide assistance as a disability-related accommodation is a paltry gesture when the promise of equality in every other social domain remains unfulfilled. There is cold comfort in the offer of death as a response to suffering and indignity within a society that overwhelmingly considers disabled lives to be, *de facto*, lives dominated by suffering and indignity.
101. For these reasons, I am of the opinion that the recognition of a legal right to suicide assistance would deliver devastating social and cultural impacts for a group already severely disadvantaged by prejudice and stigma. To move in this direction would not ameliorate disadvantage but rather entrench it, in a manner utterly inconsistent with the values expressed in the equality guarantees of the *Charter*.

102. Turning to the particular context of this case, the plaintiff, in paragraph 10 of her affidavit, bases her request for suicide assistance upon "the loss of dignity and privacy **that inevitably comes** with amyotrophic lateral sclerosis" [emphasis added]. The notion of what constitutes dignity, and what conditions of life make its loss inevitable, is therefore pivotal in the determination of her claim.
103. As detailed in paragraphs 46, 74-76 and 94-99 of this affidavit, however, bodily incapacity must not be presumed to compromise human dignity. Such a presumption negates the experience of many people with severe impairments, including people with amyotrophic lateral sclerosis, who do live with their dignity intact. To conclude that human dignity is inevitably lost when one is no longer capable of self-care, is to declare as diminished and undignified, the lives of people like myself who rely each day upon intimate human and technological support. Such a position serves to undermine the precarious claim that people with disabilities have to equality, by authenticating the devaluation of particular bodily experiences.
104. Loss of physical capacity and the concomitant need for intimate personal care do not by definition constitute 'indignity'. To accept uncritically that these states violate or diminish human dignity, is to affirm deep and long-standing patterns of thought that have relegated disabled people to the margins of social acceptance. Any measure such as assisted suicide that so squarely aligns with the fears and antipathies of a socially privileged group (people who do not require assistance with intimate personal care), must take into careful account the perspective of persons who are disadvantaged by those fears and antipathies (people who do require assistance with intimate personal care).
105. There are far reaching implications when one person's "indignity" is another person's daily routine of life. The threshold of human dignity is far too variable to be an appropriate condition for the termination of life.

106. To conclude that a request to end one's life is justified by the presumed indignity of bodily incapacity, would greatly undermine dignity as a cornerstone principle of disabled people's claim to equal status and regard within the living human family.

**Conclusion**

107. If the promise of equality for disabled Canadians is to be honoured, any consideration of legalizing physician-assisted suicide must take into careful account the context of disabled peoples' history and social reality. The social context for any claim of a 'right' to suicide assistance is a context that can be traced back in just two generations to the atrocities of a global eugenic frenzy, and in one generation to freewheeling practices of institutional confinement, involuntary sterilization and medical experimentation. It is a context that situates contemporary disabled Canadians in a social order which authorizes pandemic triage exclusion, selective genetic elimination and the withdrawal of life-supporting technologies on the basis of disability status. Disabled people constitute a group whose profound social disadvantage manifests in acts of compassion-cloaked homicide, coercion and abandonment. Violence, and social ambivalence in the face of violence, are writ large in the context and social history of disability.

108. In such a context, suicide assistance for people with disabilities cannot be considered an enabling – or neutral – accommodation.

AND I HAVE SIGNED:

**Sworn before me**  
in the city of \_\_\_\_\_,  
in the province of Nova Scotia  
this \_\_\_\_ day of September 2012.

.....  
Catherine Frazee

.....  
Commissioner for oaths