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Where have all the children gone?¹

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On April 12, 2018, the Canadian² Society (CPS) released its updated position statement entitled *Medical Assistance in Dying: A Paediatric Perspective*³, a discussion paper following the Supreme Court of Canada's 2015 decision in the *Carter* case⁴ and the subsequent implementation of Medical Aid in Dying legislation⁵ across Canada.

The position statement was developed in response to the call for submissions by the Council of Canadian Academies⁶ subcommittee on the status of "mature minors" (who are currently excluded under federal legislation), with focus on their potential eligibility for MAiD. Eligibility of mature minors was one of three areas to be studied by the CCA, along with eligibility solely for mental health reasons, and via advance directives for people with dementia, as required by the 2016 Act. The final report by the CCA is expected to be presented to Parliament by December 2018.⁷ The CPS position statement can be accessed at: <https://www.cps.ca/en/documents/position/medical->

¹ A play on the 1955 Pete Seeger Song "Where Have All the Flowers Gone?" talking about the danger of repeating cycles of history if we do not learn from the past - <http://www.indepthinfo.com/culture/where-have-all-the-flowers-gone.htm>

² "Paediatricians are specialists who focus on the physical, emotional and social health of neonates [newborns], infants, children, adolescents [teenagers] and young adults. This specialty deals with health promotion and prevention, and the detection and management of physical, behavioural, developmental, mental/emotional, environmental and social problems that affect children." <https://www.cma.ca/Assets/assets-library/document/en/advocacy/Pediatrics-e.pdf>

³ <https://www.cps.ca/en/documents/position/medical-assistance-in-dying>

⁴ Supreme Court Judgments. *Carter v. Canada (Attorney General)*, 2015-02-06, SCC 5: <https://scc-csc.lexum.com/scc-csc/scc-csc/en/item/14637/index.do> (Accessed November 7th, 2017).

⁵ Statutes of Canada 2016, Bill C-14, An Act to amend the Criminal Code and to make related amendments to other Acts (medical assistance in dying). Retrieved 16 July 2018 from <http://www.parl.ca/DocumentViewer/en/42-1/bill/C-14/royal-assent>.

⁶ (<http://www.scienceadvice.ca/en/assessments/in-progress/medical-assistance-dying/expert-panel.asp>)

⁷ <https://www.cps.ca/en/documents/position/medical-assistance-in-dying>

assistance-in-dying. Its recommendations include extensive national consultation, access to high quality palliative care and focusing on the unique risks to young people⁸.

In the event that legislation eventually permits competent minors to access MAiD, the CPS recommends that “governments at every level develop policies and procedures to safeguard young people from possible risks, harms or abuses of MAiD, given their unique vulnerabilities.”⁹ The CPS further recommends that “procedures for assessing a minor’s personal capacity to make health decisions rest with the patient’s clinical team and parents, in consultation with other designated experts (e.g., bioethicists, psychologists, psychiatrists)”¹⁰ and “the physician’s right not to participate in MAiD must be respected.”¹¹

The CPS-Attitudes survey revealed 19% of responding clinicians would be willing to provide MAiD to paediatric patients.¹² [Paediatric patients are children who are infants, toddlers, children and adolescent] Thirty-five doctors reported conversations with 60 minors about MAiD, resulting in nine explicit requests from 17 minor patients.¹³ By Contrast 118 doctors reported having conversations about MAiD with parents on behalf of 419 never-competent children [who are too disabled to ever speak on their own behalf]¹⁴. Parents made 45 explicit requests for MAiD on behalf of 91 children.¹⁵

The data would suggest a couple of things:

- a) parents are a lot more interested in killing their children than their children happen to be in dying,
- b) Some doctors are talking to a lot of people about paediatric MAiD.

There are more parents asking about MAiD for their children than there are children asking about it for themselves. Sadly, it is not children who vote or make the laws. They have no protection.

⁸ <https://www.cps.ca/en/documents/position/medical-assistance-in-dying>

⁹ <https://www.cps.ca/en/documents/position/medical-assistance-in-dying>

¹⁰ <https://www.cps.ca/en/documents/position/medical-assistance-in-dying>

¹¹ <https://www.cps.ca/en/documents/position/medical-assistance-in-dying>

¹² <https://www.cps.ca/en/documents/position/medical-assistance-in-dying>

¹³ <https://www.cps.ca/en/documents/position/medical-assistance-in-dying>

¹⁴ A really good discussion about never competent patients is contained in Chapter 2 of the Canadian Bioethics Companion. Legal competence refers to a persons ability to make medical and financial decisions and has a hard standard. Medical capacity refers to a persons ability to make decisions about their life or medical care and has a more fluid standard that can change in response to a persons level of sedation, pain, medical condition, mental health, level of consciousness, etc. This change must be continuously assessed and monitored. While there are tools to assess both competence and capacity, there is no standard tool and judges usually rely on medical professionals’ opinions. [What is missing is the lived experience of people with disabilities to present evidence about what is possible and the quality of life they could have.] <http://canadianbioethicscompanion.ca/the-canadian-bioethics-companion/chapter-2-the-doctor-patient-relationship/>

¹⁵ <https://www.cps.ca/en/documents/position/medical-assistance-in-dying>

Alberta Network for Mental Health (ANMH) endorses the Vulnerable Persons Standard¹⁶ (VPS) in order to provide maximum protection to vulnerable citizens. VPS is widely endorsed by people with disabilities. The Vulnerable Persons Standard can be accessed here (<http://www.vps-npv.ca>). The VPS Coalition does not believe MAiD services should be extended to people under age 18 because of the potential for coercion and abuse, particularly for children with disabilities.

The issues presented by the Canadian Paediatric Society position statement strike deep into the humanity of people with disabilities, in particular women and girls, whose rights and personhood are most profoundly at risk globally as outlined in an excellent discussion in the paper *Reflections on Personhood: Girls with Severe Disabilities and the Law*, by Sheila Jennings, PhD Program, Osgoode Hall Law School at York University.¹⁷

Jennings identifies quite correctly that "...the particular combination of childism, racism, sexism and ableism may work together to threaten the legal personality of some, and this ought to be a concern for children who are disabled, especially if they are female, severely disabled and very young."¹⁸

Indeed, the Convention on the Rights of Persons with Disabilities identifies in its Preamble (q), Article 6, and Article 7 the particular risk for women and girls (children) to be subjected to increased violence and discrimination.¹⁹ Jennings rightly identifies that Articles 12 - Equal Recognition Before the Law, Article 13 - Access to Justice, and Article -14 Liberty and Security of the Person are protections in the Convention that are supposed to shield citizens; yet children in care, hospitals, correctional or other institutional settings lack autonomy, agency and advocacy when they are in need of protection most.^{20 21 22 23 24 25 26 27}

¹⁶ <http://www.vps-npv.ca/>

¹⁷ <http://cjds.uwaterloo.ca/index.php/cjds/article/view/101/157>

¹⁸ <http://cjds.uwaterloo.ca/index.php/cjds/article/view/101/157>

¹⁹ Convention on the Rights of Persons with Disabilities, 24 January 2007, A/RES/61/06 (Canada acceded to on 11 March 2010) [CRPD or "the Convention"], at <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/convention-on-the-rights-of-persons-with-disabilities-2.html>.

²⁰ <http://cjds.uwaterloo.ca/index.php/cjds/article/view/101/157>

²¹ Convention on the Rights of Persons with Disabilities, 24 January 2007, A/RES/61/06 (Canada acceded to on 11 March 2010) [CRPD or "the Convention"]

²² http://ihrp.law.utoronto.ca/utfl_file/count/documents/WorkingGroup_Clinic/Cruel%20and%20Inhuman_FINAL_Print.pdf

²³ <http://www.cbc.ca/news/canada/edmonton/alberta-girl-13-failed-by-foster-care-inquiry-finds-1.1133569>

²⁴ <http://www.cbc.ca/news/health/parents-and-doctors-see-congenital-disorders-differently-1.1132627>

²⁵ <http://nationalpost.com/news/local-news/robert-latimer-mclachlin/wcm/90da0409-7d18-4ff4-982f-aa25255d6ecb>

²⁶ <http://www.cbc.ca/news/canada/new-brunswick/ashley-smith-coroner-s-jury-rules-prison-death-a-homicide-1.2469527>

²⁷ <https://web.archive.org/web/20070210031109/http://www.ccdonline.ca/law-reform/Intervention/Latimer%20factum%201997.html>

What is missing in Ms. Jennings's discussion is a thorough exploration of the rights of disabled women and girls under Article 25 - Health,²⁸ particularly Article 25 (f) pertaining to the withholding of food and fluids, a common end of life "intervention" which is a violation of the Convention.

A research paper undertaken by the Vanier Institute actually found that even when the usual emotional and financial stressors faced by parents of disabled children are taken into account:

"The general public tends to overlook many positive impacts and meaningful contributions that children with disabilities make within their families, communities and society in general."²⁹

"Children with a disability often exceeded expectations and did not necessarily comply with what is typical for their diagnoses, often being nothing close to the worst-case scenarios predicted by some doctors."³⁰

MAiD procedures are not without complications. On July 14, 1976, Capital Punishment was repealed in Canada.³¹ Capital Punishment was repealed because mistakes could be made. Procedures used to execute people are cruel, have problems and even techniques such as lethal injection cannot be accomplished without complications^{32 33}, such complications occur even in MAiD procedures.^{34 35} It is unthinkable that we now find ourselves in the place where we have made laws that call for the killing of our own citizens³⁶. That we would now consider taking the lives of our own children in the name of individual rights is unconscionable.

²⁸ Convention on the Rights of Persons with Disabilities, 24 January 2007, A/RES/61/06 (Canada acceded to on 11 March 2010) [CRPD or "the Convention"]

²⁹ <http://vanierinstitute.ca/children-disability-positive-impacts-children-family/>

³⁰ <http://vanierinstitute.ca/children-disability-positive-impacts-children-family/>

³¹ https://en.wikipedia.org/wiki/Capital_punishment_in_Canada

³² The Public Library of Science (PloS) Medicine Editors. (2007). Lethal Injection Is Not Humane. *PLoS Medicine*, 4(4), e171. <http://doi.org/10.1371/journal.pmed.0040171>

³³ "Since 1867, all civilian executions in Canada were conducted by hanging (military executions were traditionally by shooting), though there were some experiments in variations of hanging methods in 1890 the traditional long drop was the standard until abolition of the death penalty for ordinary crimes in 1976." <https://www.amnesty.ca/our-work/issues/abolish-the-death-penalty/death-penalty-in-canada>

³⁴ <https://canadiem.org/medical-assistance-dying-maid-ed-part-ii/>

³⁵ A study published in the year 2000 in the New England Journal of Medicine gathered data from three other researchers and looked at the problems with the administration of assisted suicide and euthanasia in the Netherlands. In total, there were complications with 13% of the euthanasia deaths and 31% of the assisted suicides. Overall, there were problems in 16% of the medical killings studied. Groenewoud, Johanna H., M.D. et al, Clinical Problems with the Performance of Euthanasia and Physician Assisted Suicide in the Netherlands, *NEJM* Vol. 342 No. 8, February 24, 2000, Retrieved 17 July 2018 from <https://www.nejm.org/doi/full/10.1056/NEJM200002243420805>

³⁶ Supreme Court Judgments. *Carter v. Canada (Attorney General)*, 2015-02-06, SCC 5: <https://scc-csc.lexum.com/scc-csc/scc-csc/en/item/14637/index.do> (Accessed November 7th, 2017)

Gerhard Kretschmar was a boy born with disabilities to Richard and Lina Kretschmar on 20 February 1939 who was euthanized at the request of his parents³⁷. They wrote a letter to Adolf Hitler who granted their request through an order to his personal physician on 25 July 1939³⁸. From this single act, an operation called Aktion T-4 was created in which between 5,000 - 8,000 children with disabilities were killed³⁹. "Consent" of the parents was dispensed with as the program expanded⁴⁰. Rights of young people were certainly not a factor for they were not considered human⁴¹. As the operation expanded, Germany killed 240,000 of its disabled citizens, who were seen as "life unworthy of life". People with intellectual disabilities, psychosocial disabilities, homeless people, Jews, gypsies, Jehovah's Witnesses, gays were all slated for death as the net grew. Aktion T-4 led to the perfection of the killing methods for the Holocaust⁴² where 17,000,000 people died⁴³; 1.1 million of these people were children.⁴⁴

117,316 Canadian soldiers have died from WW1 to the present day defending the rights of Canadian people as well as millions of people who were imprisoned, displaced and killed in the tyranny of Aktion T-4 and other genocides to protect those who could not fight for themselves.⁴⁵ We will remember them.

As the title of our paper would caution us, failing to learn from history by linking human value to civic or economic return on investment is a cautionary tale:

"Today's arguments over the rationing of health care services to include an economic lens on the value or civic return on investment rather than their need for treatment.⁴⁶ We should be mindful of where this has gotten us in the past".⁴⁷

And today, why it is vital to reflect upon:

³⁷ https://en.wikipedia.org/wiki/Gerhard_Kretschmar

³⁸ https://en.wikipedia.org/wiki/Gerhard_Kretschmar

³⁹ Hudson, Lee, From Small Beginnings: The euthanasia of children with disabilities in Nazi Germany, *Journal of Paediatrics and Child Health Division (Royal Australian College of Physicians)*, 47 - (2011) p 508-511

⁴⁰ Hudson, Lee, From Small Beginnings: The euthanasia of children with disabilities in Nazi Germany, *Journal of Paediatrics and Child Health Division (Royal Australian College of Physicians)*, 47 - (2011) p 508-511

⁴¹ Hudson, Lee, From Small Beginnings: The euthanasia of children with disabilities in Nazi Germany, *Journal of Paediatrics and Child Health Division (Royal Australian College of Physicians)*, 47 - (2011) p 508-511

⁴² Hudson, Lee, From Small Beginnings: The euthanasia of children with disabilities in Nazi Germany, *Journal of Paediatrics and Child Health Division (Royal Australian College of Physicians)*, 47 - (2011) p 508-511

⁴³ https://en.wikipedia.org/wiki/The_Holocaust

⁴⁴ <https://www.dosomething.org/us/facts/11-facts-about-holocaust>

⁴⁵ <http://www.veterans.gc.ca/eng/news/general-statistics>

⁴⁶ Hudson, Lee, From Small Beginnings: The euthanasia of children with disabilities in Nazi Germany, *Journal of Paediatrics and Child Health Division (Royal Australian College of Physicians)*, 47 - (2011) p 508-511

⁴⁷ Hudson, Lee, From Small Beginnings: The euthanasia of children with disabilities in Nazi Germany, *Journal of Paediatrics and Child Health Division (Royal Australian College of Physicians)*, 47 - (2011) p 508-511

“...how we as individuals and as a society react to adults and children with disabilities. The nameless stranger with a disability in the street can evoke an array of emotional responses including pity, anger, frustration, and confusion, until we know that person as an individual, as part of our family, as our friend, our colleague, or as our patient. Today, as under the Nazis, children and adults with disabilities are sometimes considered *outside* of society rather than *part of it*, and in so doing, may be seen as a burden or apportioned blame. Blame can be a natural response to disability or any illness that frustrates us (this patient is not trying or not complying). Blame alleviates our civic and moral shame, which diminishes our civic or moral responsibility. If we are not careful, this can lead to their neglect, or in the case of the Nazis, their destruction.”⁴⁸

We also remember Tracy Latimer, a girl with cerebral palsy killed by her father, Robert Latimer, out of “necessity to end her suffering”.⁴⁹ Policy advice should not be sought from Robert Latimer. He is now also writing his own letter to our Prime Minister,⁵⁰ and is seeking a pardon from the minister of Justice.⁵¹

The dangers of considering children’s mere civic value without first ensuring their civil rights are upheld are highlighted further in Ms Jennings’ paper where she cautions:

“One form in which a lesser value reveals itself is when the state fails to ensure that all children have realized their full and equal legal rights across domains. As noted above, children with severe disabilities do not enjoy the same legal rights as non-disabled children. Moreover, there are questions that arise with respect to their rights that crop up before children’s hospital ethics boards, in neonatal intensive care units, in child welfare courts, in criminal cases, in schools and elsewhere that call out for further attention.”⁵²

In this same way, people with disabilities, women and girls in particular, lack basic human rights many Canadians take for granted.^{53 54} Without having access to essential supports and services, and having internalized the attitudes of the colleagues, it is a travesty of justice they have internalized the ableist attitudes of society and now in the name of individual rights are seeking to die. Not one dollar should be spent creating laws to kill our own citizens before spending dollars to provide supports and services

⁴⁸ Hudson, Lee, From Small Beginnings: The euthanasia of children with disabilities in Nazi Germany, *Journal of Paediatrics and Child Health Division* (Royal Australian College of Physicians), 47 - (2011) p 508-511

⁴⁹ *R. v. Latimer*, [2001] 1 S.C.R. 3, 2001 SCC 1

⁵⁰ <http://thestarphoenix.com/news/local-news/robert-latimer-mclachlin>

⁵¹ Retrieved 17 July 2018 from <https://bc.ctvnews.ca/robert-latimer-seeking-pardon-for-killing-of-severely-disabled-daughter-1.4010650>

⁵² JENNINGS, Sheila K. Reflections on Personhood: Girls with Severe Disabilities and the Law. *Canadian Journal of Disability Studies*, [S.l.], v. 2, n. 3, p. 55-97, sep. 2013. ISSN 1929-9192. Available at: <<http://cjds.uwaterloo.ca/index.php/cjds/article/view/101/157>>. Date accessed: 12 Nov. 2017. doi:<http://dx.doi.org/10.15353/cjds.v2i3.101>.

⁵³ <https://web.archive.org/web/20070210031109/http://www.ccdonline.ca/law-reform/Intervention/Latimer%20factum%201997.html>

⁵⁴ Convention on the Rights of Persons with Disabilities, 24 January 2007, A/RES/61/06 (Canada acceded to on 11 March 2010) [CRPD or “the Convention”]

necessary to provide essential services and supports to sustain and support the safe and effective lives of people with disabilities.⁵⁵ ⁵⁶ We hope, that like capital punishment, one day Medical Aid in Dying will be repealed.

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⁵⁵ <http://www.parl.ca/DocumentViewer/en/42-1/PDAM/meeting-12/evidence#Int-8782476>

⁵⁶ <https://sencanada.ca/Content/SEN/Committee/421/ljc/pdf/09issue.pdf>