

Mature Minor Eligibility for Medical Assistance in Dying (MAiD): An Ethical Analysis

by

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Author's Declaration

I hereby declare that I am the sole author of this thesis. This is a true copy of the thesis, including any required final revisions, as accepted by my examiners.

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Abstract

Medical Assistance in Dying (MAiD) was legalized in Canada on June 17, 2016, following a landmark Supreme Court of Canada decision, *Carter v. Canada* (2015). Currently, the law controversially denies three groups access to MAiD: mature minors (capable children under 18), persons making advance directives, and persons with mental illness as a sole underlying condition. All three populations are excluded from access to MAiD on the grounds that they may lack the capacity to autonomously request and consent to the procedure.

This Applied Philosophy Dissertation examines the prospect of extending MAiD eligibility to one of these vulnerable populations, mature minors. The question of MAiD presents conflicting legal and ethical obligations to children. One obligation is to child welfare. We have stronger duties – including legal duties – to protect children’s interests than those of adults, and we organize society such that children are treated differently to shield them as a vulnerable group. Yet we also have obligations to child self-determination. Children have a legal right to decision-making autonomy corresponding to their level of maturity. This tension between welfare and self-determination hinges in part on whether children can make genuinely autonomous choices, a source of considerable debate among child development experts.

The dissertation argues that eligibility for MAiD should be calibrated according to maturity rather than age. It develops three key arguments for this conclusion. One is that an age criterion in Bill C-14 is an unjustifiable act of age discrimination. Children who are otherwise eligible for MAiD suffer to the same extent as adults, and are disadvantaged compared to adults where they cannot end this suffering on their own terms. Secondly, prohibiting mature minors from accessing MAiD does not protect their welfare, and may be harmful in cases where requests are motivated by severe pain and suffering, a low quality of life, and an unwillingness to endure continued indignities. Thirdly, the law treats mature minors inconsistently by permitting minors to refuse life-sustaining treatment, for example, a blood transfusion on religious grounds, yet prohibiting them from consenting to MAiD. This legal inconsistency is also an ethical inconsistency: mature minors are able to choose to die when they could otherwise live, yet they are unable to control how they die when their death is unavoidable.

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Chapter 1

Introduction and Legal Background

On June 17, 2016, Bill C-14, “an Act to Amend the Criminal Code and to Make Related Amendments to Other Acts (Medical Assistance in Dying)” received royal assent, decriminalizing Medical Assistance in Dying (MAiD) in Canada. Prior to the amendments made under Bill C-14, two provisions of the Criminal Code prohibited the provision of MAiD. Section 241 (b) stated that everyone who aids or abets a person in committing suicide commits an indictable offence (1985). Meanwhile, s. 14 stated that no person may consent to death being inflicted on them (Criminal Code, 1985). Two legal cases were instrumental in decriminalizing MAiD in Canada: *Rodriguez v. British Columbia AG* (1993), and *Carter v. Canada* (2015).

These cases raise challenges balancing values of patient autonomy and protecting the vulnerable, along with questions of expanding MAiD to new populations. This chapter begins by providing background on the Rodriguez and Carter decisions, and describing the legislative framework under Bill C-14. The work then discusses ethical issues under Bill C-14, including questions of whether MAiD devalues the sanctity of life, if safeguarding can protect the vulnerable, equality, and persons with disabilities, whether physicians who conscientious objects to MAiD are obligated to refer their patients, and whether MAiD is a slippery slope to decriminalizing homicide. The chapter then considers ethics issues for the three issues for independent review under Bill C-14: advance directives, mental illness as sole underlying condition, and mature minors. Lastly, the chapter reviews challenges to the law post Bill C-14, including *Lamb v. Canada (AG)* and *Truchon c. Procureur Général du Canada*, and describes new amendments to the law under Bill C-7.

1.1 *Rodriguez v. British Columbia (AG) (1993)*

In 1993, the appellant, Sue Rodriguez, was a 42-year-old mother who suffered from amyotrophic lateral sclerosis (ALS) (*Rodriguez v. BC* 1993, p 520d). Her condition was rapidly deteriorating, and she was faced with a life expectancy of between two and fourteen months (*Rodriguez v. BC* 1993, p 520e). Further, she anticipated losing the abilities to swallow, speak, walk, move her body without assistance, breathe without a respirator, and eat without a gastronomy tube in the near future – eventually becoming confined to a bed (*Rodriguez v. BC* 1993, p 520d). Not wishing to die so long as she still has the capacity to enjoy life, Rodriguez nonetheless wished that a qualified physician be allowed to set up technological means by which she might, when she is no longer able to enjoy life, by her own hand and at the time of her choosing, end her life (*Rodriguez v. BC* 1993, p 520e–f). Hence, she applied to the Supreme Court of British Columbia for an order that s. 241 (b) of the Criminal Code be declared invalid on the ground that it violated her rights under ss. 7, 12, and 15(1) of the Charter, and is of no force and effect by virtue of s. 52(1) of the Constitution Act, 1982 (*Rodriguez v. BC* 1993, p 520f–g).

Section 7 of the Charter guarantees the right to life, liberty, and security of the person and the right not to be deprived thereof except in accordance with the principles of fundamental justice (Canadian Charter, 1982, s. 7). Section 7 of the Charter was engaged on the basis of an alleged violation of the appellant’s liberty and security-of-the-person interests (*Rodriguez v. BC* 1993, p 520i). Rodriguez argued that liberty was engaged insofar as she had the right to make choices concerning her own body, and to be free from governmental interference in making fundamental personal decisions (*Rodriguez v. BC* 1993, p 583hi). Security of the person was engaged for similar reasons, yet from the perspective of preserving her personal autonomy through control over her physical and psychological integrity, and the right to basic human dignity (*Rodriguez v. BC* 1993, p 521a).

Under section 12, everyone has the right not to be subjected to any cruel and unusual treatment or punishment (Canadian Charter, 1982, s. 12). In her case, Sue Rodriguez argued that the prohibition on physician-assisted death had the effect of imposing cruel and unusual treatment, as she was faced with the impossible choice of enduring prolonged suffering until her natural death, or ending her life prematurely (*Rodriguez v. BC* 1993, p 609a). Meanwhile, section 15(1) guarantees that every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age, or mental or physical disability (Canadian Charter, 1982, s.

15). Section 15(1) is engaged because s. 241 of the Criminal Code has the effect of creating an inequality of depriving physically disabled persons of the right to choose suicide (Rodriguez v. BC 1993, p 524i). In effect, Rodriguez argued that by denying her control over the manner and timing of her death, the law violated her autonomy, subjected her to cruel and unusual treatment, and was discriminatory on the basis of physical disability.

In a 5-4 majority against Sue Rodriguez, the SCC ruled that section 241 (b) of the Criminal Code was constitutional (Rodriguez v. BC 1993, p 520h). The majority argued that s. 241 (b) of the Criminal Code did not violate s. 7 of the Charter, as any infringement on the liberty and security of the person is not arbitrary: the prohibition on physician-assisted dying relates to the state's interest in protecting vulnerable persons, and this reflects fundamental values in Canadian society (Rodriguez v. BC 1993, p 522e). Further, the majority argued that s. 241 (b) of the Criminal Code did not constitute cruel and unusual punishment, because a prohibition is generally not classified as 'treatment' within the meaning of s. 12 ('treatment' refers to an active state process which exercises state control over the individual) (Rodriguez v. BC 1993, p 522f-g). With regard to s. 15, the majority chose not to deliberate upon whether there was a s. 15 violation but rather to assume there is one, because they argued that any infringement of s. 15 is clearly justified under s. 1 of the Charter¹ as a law to protect and maintain respect for life (Rodriguez v. BC 1993, p 522i-j). Thus Rodriguez's arguments were unsuccessful at the SCC, which determined that concerns for autonomy are justified by welfare considerations. Any s. 7 violation of autonomy under the law is justified by the state's interests in protecting the vulnerable. Further, as it does not entail an active treatment intervention, the law cannot be considered to impose cruel and unusual punishment on an individual. Finally, the SCC assumed that the law discriminates on the basis of disability, but found this violation is justified by s. 1 of the Charter.

¹ The guarantee of Charter rights and freedoms is subject to reasonable limits prescribed by law as can be demonstrably justified in a free and democratic society (Canadian Charter, 1982, s. 1).

1.2 *Carter v. Canada (AG)* (2015)

Nineteen years after *Rodriguez v. British Columbia (AG)* (1993) decision, a similar challenge was brought by Gloria Taylor, Hollis Johnson, and Lee Carter. In 2009, Gloria Taylor was diagnosed with ALS. Like Sue Rodriguez, Taylor did “not want to die slowly, piece by piece” or “wracked with pain” (*Carter v. Canada*, 2012, par. 11). She brought a claim before the British Columbia Supreme Court challenging the constitutionality of sections 14 and 241(b) of the Criminal Code, among other provisions that prohibit assistance in dying (*Carter v. Canada*, 2012, par. 101). Lee Carter and Hollis Johnson, who had assisted Ms. Carter’s mother, Kathleen (“Kay”) Carter, in achieving her goal of dying with dignity through an assisted suicide clinic in Switzerland, also joined Ms. Taylor in her claim (*Carter v. Canada*, 2012, par. 11). The claim was also joined by Dr. William Shoichet, a physician from British Columbia who would be willing to participate in physician-assisted dying if it were no longer prohibited; and by the British Columbia Civil Liberties Association (*Carter v. Canada*, 2012, par. 11). The plaintiffs challenged the assisted-suicide prohibition, arguing that, to the extent that the provisions prohibit physician-assisted dying, they unjustifiably infringe sections 7 and 15 of the Canadian Charter of Rights and Freedoms (*Carter v. Canada*, 2012, par. 22).

The nature of the plaintiffs’ argument was interpreted according to *Rodriguez*, as it remained a binding authority with respect to certain aspects of the plaintiffs’ claims (*Carter v. Canada*, 2012, par. 12). According to *Rodriguez*, s. 241 (b) of the Criminal Code engages Gloria Taylor’s rights to liberty and security of the person, and possibly her right to life as she may take her own life prematurely while she is still physically able to do so – thus shortening her lifespan (*Carter v. Canada*, 2012, par. 17). Section 241 (b) also engages Lee Carter and Hollis Johnson’s rights to liberty because it puts them at risk of incarceration for helping a loved one obtain assisted death in Switzerland (*Carter v. Canada*, 2012, par. 17).

The s. 15 claim was similar to that in *Rodriguez*. The plaintiffs argued that physically disabled persons who cannot commit suicide without help are denied the option of suicide, a practice that is not legally prohibited in Canada (*Carter v. Canada*, 2012, par. 15). Thus, provisions regarding assisted suicide have a more burdensome effect on persons with physical disabilities than on able-bodied persons, and thereby create the effect of a discriminatory distinction based on physical disability that perpetuates disadvantage (*Carter v. Canada*, 2012, par. 15). This claim is not substantiated by the *Rodriguez* judgement as the s. 7 claims were. After all, the SCC did not deliberate whether s. 241 (b) of the Criminal Code violated s. 15 Charter rights, and instead assumed

a s.15 violation and concluded that any violation is saved by s. 1 of the Charter (see the summary of *Rodriguez v. British Columbia AG*, p. 3). In summary, the argument made by the plaintiffs in *Carter v. Canada* similarly appealed to principles of autonomy and equality, yet also argued that the law limits the right to life by forcing some individuals to take their lives prematurely.

In a departure from their 1993 ruling in *Rodriguez*, the Supreme Court ruled in favour of the plaintiffs, and found that Sections 241 (b) and 14 of the Criminal Code

unjustifiably infringe upon section 7 of the Charter and are of no force or effect to the extent that they prohibit physician-assisted death for a competent adult person who (1) clearly consents to the termination of life and (2) has a grievous and irremediable medical condition (including an illness, disease or disability) that causes enduring suffering that is intolerable to the individual in the circumstances of his or her condition. (*Carter v. Canada*, 2015, par. 147)

The SCC issued a declaration that s. 14 and s. 241 (b) are invalid to the extent they deny s. 7 rights for people like Gloria Taylor (*Carter v. Canada*, 2015, par. 147). They also suspended this declaration for one year to allow the government to reconcile the Charter rights of patients and physicians with a mandated legislative or regulatory response to the judgement (*Carter v. Canada*, 2015, par. 132).

1.3 A Moral Shift from Rodriguez to Carter

The Supreme Court's decision to depart from its previous decision in Rodriguez was unusual given the similar adjudicative facts of Carter: Ms. Rodriguez, like Ms. Taylor, was dying of ALS and wanted the right to seek a physician's assistance in dying. The SCC considered this departure in terms of the principle of stare decisis, the fundamental legal doctrine which dictates that lower courts must follow the decisions of higher courts. In Carter 2012, the Court of Appeal had decided to allow Canada's appeal on grounds that stare decisis should be observed, and thus the trial judge in the Carter case was bound to follow the SCC decision in Rodriguez (Carter v. Canada, 2015, par. 34). Yet as established in *Canada AG v. Bedford*, trial courts may reconsider settled rulings of higher courts in two situations. One is where a new legal issue is raised, and the other is where there is a change in circumstance and evidence that fundamentally shifts the parameters of the debate (Carter v. Canada, 2015, par. 44). The SCC found in Carter 2015 that both situations were met in the trial stage, and that it was appropriate for the trial judge to depart from the ruling in Rodriguez.

The first situation was met because the argument that was brought before the trial judge in Carter applied a different legal conception of s. 7 than in Rodriguez, applying a different principle of fundamental justice to the problem that s. 14 and s. 241 b of the Criminal Code were "over-inclusive" – that is, they extended outside the class of vulnerable persons the law was meant to protect. In Rodriguez v. BC (1993), the Supreme Court of Canada contemplated the prohibition's arbitrariness or unfairness (Carter v. Canada, 2015, par. 46). According to the principles of fundamental justice, an arbitrary deprivation of s. 7 rights occurs where the law bears no connection to the law's purpose (Department of Justice, 9).

Analysis in *Carter v. Canada* characterized overbreadth as the more appropriate principle of fundamental justice to address the problem of over-inclusiveness. The principle of overbreadth applies to a law so broad in scope that some of its impacts are rationally connected to its purpose, but it also captures some conduct that bears no relation to the legislative objective – and thus overreaches its purpose (Department of Justice, 9; Canada AG v. Bedford, 2013, par. 112).

An example of a law violating the principle of overbreadth is the law at issue in *R. v. Demers* (2004). In *R. v. Demers*, the appellant challenged legislation under the Criminal Code which required persons accused yet deemed unfit to stand trial to attend repeated review board hearings (*R. v. Demers*, 2004, par. 1–2). Under the impugned legislation, the unfit accused would be subject to yearly hearings by the courts or by a review board until "(a) he or she becomes fit to stand trial or (b)

the Crown fails to establish a prima facie case against him or her” (R. v. Demers, 2004, par. 13). The review board was not authorized to grant absolute or unconditional discharge² to an accused unfit to stand trial (R. v. Demers, 2004, par. 11). The objective of the legislative scheme was to provide individual assessment and opportunities for appropriate treatment for the accused to become fit for an eventual trial while preserving their maximum liberty and dignity. This objective applied to cases where the unfit accused does not suffer from a permanent mental disorder, and trial remains a possibility. Yet it could not apply in a case of a permanently unfit accused, where trial is not a possibility (R. v. Demers, 2004, par. 42). The Supreme Court of Canada determined that the continued subjection of an unfit accused to the criminal process, where there is clear evidence that capacity will never be recovered and there is no evidence of a significant threat to public safety, is overbroad (R. v. Demers, 2004, par. 43). This is because repeated review board hearings are not the least restrictive means to a permanently unfit accused’s liberty and are not necessary to achieve the state’s objective (R. v. Demers, 2004, par. 43).

The principle of overbreadth could not have been applied at the time of Rodriguez, as it was not yet explicitly recognized as a principle of fundamental justice (Carter v. Canada, 2015, par. 46; Department of Justice, 9). Since overbreadth is recognized as a principle of fundamental justice at the time of *Carter* (2015), the SCC could approach the issue with a new question engaging s. 7, which could viably lead to a different ruling than in Rodriguez. Rather than asking the question considered in Rodriguez on whether a prohibition on physician-assisted death is arbitrary by being unrelated to the state’s interest in protecting the vulnerable or by having inadequate foundation in the legal tradition and societal beliefs it represents, Carter considers a new legal issue by asking whether the prohibition on physician-assisted death interferes with some conduct that has no connection with the law’s objectives (Carter v. Canada 2015, par. 46).

This shift in the legal conception of s. 7 also shifts the relevant ethical questions engaged by the cases. By contemplating whether s. 14 and s. 241 of the Criminal Code are arbitrary, the SCC balanced the state’s duty to protect the sanctity of life with the patient’s right to autonomy and dignity. Further, because s. 7 was not found to be violated in Rodriguez, equality violations were considered – engaging ethical questions about discrimination against persons with disabilities. Meanwhile in Carter, the ethical issues considered centre on whether s. 14 and s. 241 are overly broad. This legal issue engaged moral questions about dignity, autonomy, quality of life, and the role

² The exception is where individuals are declared NCR.

of prohibitions in encouraging harmful behaviour for those outside the class of persons the law was meant to protect.

The second situation enabling trial courts to reconsider settled rulings of higher courts is also met because the SCC evaluated that evidence given in the trial stage could undermine key conclusions made in *Rodriguez* about the legislative and social facts of the issue. In *Rodriguez* the SCC relied on evidence of

(1) the widespread acceptance of a moral or ethical distinction between passive and active euthanasia; (2) the lack of any “halfway measure” that could protect the vulnerable; and (3) the “substantial consensus” in Western countries that a blanket prohibition is necessary to protect against the slippery slope. (*Carter v. Canada*, 2015, par. 47)

The SCC found that each of these had changed in the intervening years. Where the majority ruled in *Rodriguez* that decriminalizing assisted suicide cannot be said to represent a consensus of Parliament nor of the Canadian public, there has since been evidence of widespread public support for the practice (*Downie and Bern*, p 32). The legislative landscape on the issue had also changed. Although no other Western democracy expressly permitted assistance in dying in 1993, eight jurisdictions permitted some form of assisted dying by 2010 (*Carter v. Canada*, 2015, par. 8). Since then, some of these jurisdictions have expanded their laws, and more jurisdictions have passed laws to permit forms of assisted dying (see Table 1 in the Appendix).

Within Canada, public support for decriminalizing aid in dying has grown. The Royal Society of Canada Expert Panel on End of Life Decision Making demonstrated significant support amongst the general public for both voluntary euthanasia and assisted suicide (*Schuklenk et al.*, p 24). A 2010 Angus Reid survey of a national sample of 1,003 Canadians found that 67% of respondents were in favour of legalizing voluntary euthanasia (*Schuklenk et al.*, p 24). Aid in dying had also become an increasing legislative topic of debate in Canada. Although none were passed, six private member’s bills seeking to decriminalize assisted suicide were debated in the House of Commons between 1991 and 2010 (*Carter v. Canada*, 2015, par. 6). Opponents of legalizing assisted suicide argued before the Court that it had a potential to devalue human life, and that safeguards to the practice were inadequate (*Carter v. Canada*, 2015, par. 6). Those in favour of legalizing the practice, meanwhile, “highlighted the importance of dignity and autonomy and the limits of palliative care in addressing suffering” (*Carter v. Canada*, 2015, par. 6).

In considering whether the trial judge's decision in *Carter* was bound to the *Rodriguez* decision according to *stare decisis*, the SCC determined that a departure from the *Rodriguez* decision was largely justified by a change in the perceived moral status of physician-assisted death. This change occurred through a shift in the moral framing of the issue; through a different legal conception of the principles of fundamental justice, and also through evidence of a moral shift in Canadian society.

1.3.1 The Carter Decision: A Decision of Significant Ethical Relevance

While the legality of MAiD was addressed in *Carter*, the SCC decision offered an ethical position on the morality of the practice – which is debated among public and professional interest groups. Procedurally, SCC interpretations of the Charter of Rights and Freedoms have a moral dimension, as they are meant to be reflective of Canadian values. Pierre Elliot Trudeau's vision was that the common bond of Canadian citizenship could be defined through a constitutional charter of rights expressing the values shared by all Canadians (Bateman et al., p 5). In 2007, reflecting on the Charter 25 years after its adoption in 1982, Chief Justice Beverly McLaughlin remarked that this vision has been upheld, stating that “the Charter affirms ... the fundamental rights that bind us to each other and ground our identity as Canadians” (pp 366–367).

The SCC claimed that the question brought before them in *Carter* is one of balancing competing values of autonomy and dignity with the sanctity of life and the need to protect the vulnerable (*Carter v. Canada*, 2015, par. 2). ‘Vulnerability’ in this context, while challenging to define, refers to a heightened decisional risk that persons without a “rational and considered desire for death” will choose to die” (*Carter v. Canada*, 2015, par. 114). In particular, the Supreme Court of Canada identify “cognitive impairment ... mental illness, coercion, undue influence, psychological or emotional manipulation, systemic prejudice ... and ambivalence or misdiagnosis” (*Carter v. Canada*, 2015, par. 114) as factors which could leave patients decisionally vulnerable and which therefore could be grounds for exclusion from eligibility. The SCC argues in *Carter* that while the sanctity of life is one of our most fundamental societal values, with Section 7 being rooted in a profound respect for the value of human life, this does not justify an absolute prohibition on assisted death, as the law also recognizes that in certain circumstances an individual's choice about the end of her life is entitled to respect (*Carter v. Canada*, 2015, par. 63).

The Supreme Court of Canada ruled that ss. 241 (b) and 14 of the Criminal Code unjustifiably infringe upon s. 7 rights to life, liberty, and security. A prohibition on MAiD engages the right to life as a law which imposes an increased risk of death on a person, directly or indirectly, by “having the

effect of forcing some individuals to take their own lives prematurely, for fear that they would be incapable of doing so when they reached the point where suffering was intolerable” (Carter v. Canada, 2015, par. 56–58). Moreover, the Supreme Court found that a right to life does not necessitate an absolute prohibition on assistance in dying, which would create a duty to live rather than a right to life (Carter v. Canada, 2015, par. 63). A prohibition on MAiD likewise interferes with patients’ ability to make decisions concerning their bodily integrity and medical care, thus infringing on their right to liberty (Carter v. Canada, 2015, par. 65). Lastly, by allowing persons requesting MAiD to endure intolerable suffering, an absolute prohibition on MAiD infringes on their right to security of the person (Carter v. Canada, 2015, par. 65). The law violates the principle of fundamental justice of overbreadth, as the law overreaches its objective to protect vulnerable persons from being induced to commit suicide in a time of weakness by limiting the s. 7 rights of persons who are competent, fully informed, and free from coercion or duress (Carter v. Canada, 2015, par. 86).

The Supreme Court considered, yet ultimately decided against, the prospect of issuing a free-standing constitutional exception from the application of the Criminal Code (Carter v. Canada, 2015, par. 124). A free-standing constitutional exemption would mean that the Criminal Code would not be amended, but there would be a judicial mechanism for the relatively small number of individuals who are extraordinarily affected by the law to access MAiD on an exceptional basis (Carter v. Canada, 2015, par. 124). The objective of a constitutional exemption is to avoid blunt overhauls of the law by providing individual remedies in rare cases where the application of the law offends the Charter (*R. v. Ferguson*, 2008, par. 39). The Supreme Court drew upon the reasoning in *R. v. Ferguson* (2008) to argue that issuing a constitutional exemption would result in the courts using discretion to reject laws which Parliament prescribes, and keeping laws on the books that risk unconstitutional treatment of Canadians (Carter v. Canada, 2015, par. 125; *R. v. Ferguson*, 2008, par. 40–69). This would create uncertainty, undermine the rule of law, and usurp Parliament’s role (Carter v. Canada, 2015, par. 125; *R. v. Ferguson*, 2008, par. 40–69). Based on this reasoning, the Supreme Court ruled that Carter was not a proper case for a constitutional exemption and that Parliament must be given the opportunity to craft an appropriate remedy for the law’s infringement on s. 7 rights (Carter v. Canada, 2015, par. 125).

The Supreme Court of Canada issued a declaration of invalidity that ss. 241(b) and 14 of the Criminal Code are void insofar as “they prohibit physician-assisted death for a competent adult person who (1) clearly consents to the termination of life and (2) has a grievous and irremediable

medical condition (including an illness, disease or disability) that causes enduring suffering that is intolerable to the individual in the circumstances of his or her condition” (Carter v. Canada, 2015, par. 127). This declaration of invalidity was suspended for one year to give time for Parliament to craft a legislative response to the decision (Carter v. Canada, 2015, par. 128). The Supreme Court of Canada later granted a four-month extension to accommodate a change in government within the one-year suspension (the Liberal Party replaced the Conservative Party) (Downie and Chandler, 2018, p 5).

1.4 Bill C-14: A Response to the Carter Decision

On June 17, 2016, roughly 15 months after the Carter decision, a legislative response was given through Bill C-14 (see Fig. 1 in the Appendix) which amended the Criminal Code in a few ways. First, in order to permit medical practitioners and nurse practitioners to provide medical assistance in dying and to permit pharmacists and other persons to assist in the process, Bill C-14 makes exemptions from the following criminal offences: culpable homicide, aiding suicide, and administering a noxious thing. Second, Bill C-14 specifies the eligibility criteria and safeguard conditions necessary for MAiD provision. Third, for the purpose of monitoring MAiD, medical practitioners and nurse practitioners who receive MAiD requests and pharmacists who dispense substances in connection with the provision of MAiD must provide relevant information. Further, the Minister of Health is given authorization to make regulations on the basis of that information. Fourth, C-14 creates new offences for failing to comply with the safeguards, forging or destroying documents related to medical assistance in dying, failing to provide the required information, and contravening the regulations governing MAiD.

The legislation outlines a number of safeguards to protect the vulnerable. To receive MAiD, a patient must make a written request for MAiD which they have signed and dated, after being informed that they have a grievous and irremediable medical condition and that they may, at any time and in any manner, withdraw their request. If the person is physically unable to sign their written request, an “authorized third person” who is at least 18 years of age, understands the nature of the request for MAiD and does not know or believe they will benefit from the person’s death³ may sign and date the request under the person’s express direction. The written request must be signed and

³ That is, they are not a beneficiary under the will of the person making the request, or a recipient in any other way of a financial or other material benefit resulting from that person’s death.

dated in front of two independent witnesses who are at least 18 years of age, understand the nature of the request for MAiD, do not know or believe that they will benefit from the person's death,³ do not own or operate any health care facility where the person is being treated or resides, and are not directly involved in providing health care or personal care to the person making the request.

Two assessments provided by two independent physicians or Nurse Practitioners (NPs) to verify that the patient meets eligibility criteria. To be independent, the other physician/NP cannot be their mentor, or supervise their work, they may not know or believe they will benefit from the person's death other than standard compensation for their services, and they are not connected to the other practitioner or to the person making the request in any other way that would affect their objectivity. There must be at least ten clear days between the day the request is signed and the provision, which can be shortened if both physicians/NPs are of the opinion that the person is at risk of imminently losing capacity. Immediately before providing MAiD, the person must have an opportunity to withdraw their request and give express consent to the procedure. All necessary measures to provide a reliable communication must be given if the person has difficulty communicating their decision.

A controversial aspect of Bill C-14 are the amendments to section 241(b) which specify eligibility for MAiD (listed as 241.2 (1-2) in Bill C-14). The general criteria are listed under sections 241.2 (1). To be eligible to receive MAiD in Canada, a person must be eligible for health services funded by a government in Canada; and at least 18 years of age and capable of making decisions with respect to their health (Bill C-14, 241.2 (1)). Further, they must have a grievous and irremediable medical condition, they must make a voluntary request for MAiD which is not influenced by external pressure, and they must give informed consent to receiving MAiD after having been informed of alternative options to relieve suffering (including palliative care) (Bill C-14, s. 241.2 (1)). Section 241.2 (2) defines 'grievous and irremediable medical condition' with a set of further criteria. To qualify as having a grievous and irremediable medical condition, a person must have a serious and incurable illness, disease, or disability; they must be in an advanced state of irreversible decline in capability; they must be enduring physical or psychological suffering, as a result either of their illness, disease, or disability or of their decline in capability, which is intolerable to them and which cannot be relieved under conditions that they consider acceptable. Lastly, their natural death must be reasonably foreseeable, though the legislation does not specify a maximum life expectancy that characterizes a "reasonably foreseeable natural death."

Sections 241.2 (1(b), (c), (d), and (e)), of Bill C-14 emphasize adult capability and competency as necessary conditions to be eligible for MAiD, and implicitly restrict patients with mental illness as a sole underlying condition from accessing MAiD through the reasonably foreseeable natural death eligibility requirement. These requirements have been criticized for narrowing eligibility to reflect the characteristics of claimants in Carter – that is, capable adults who would remain competent while they faced significant physical decline. In the Carter decision, the Supreme Court claimed that the scope of their declaration is intended to respond to the factual circumstances in this case, and makes no pronouncement on other situations where physician-assisted dying may be sought. Bill C-14 therefore outlines three cases where issues related to requests must be subject to independent review to gather evidence and study the question of permitting MAiD for such groups: mature minors, advance requests, and mental illness as a sole underlying condition.

1.4.1 Two-Stage Legislative Process

Complying with recommendations from the Special Parliamentary Joint Committee, the Government of Canada undertook a two-stage legislative process. The first stage, outlined in Bill C-14, applied immediately to competent adult persons 18 years or older. This legislative response to the Carter decision may be followed by a second stage applying to patients wishing to make advance directives, patients with mental illness as a sole underlying condition, and mature minors – based on a review of evidence presented to each House of Parliament no more than two years after the first stage (Bill C-14). In accordance with Bill C-14, the Government of Canada undertook an independent review facilitated by the Council of Canadian Academies, with a report released in December 2018, of the moral, medical, and legal issues regarding these outstanding issues (CCA, 2016). In part, this review was conducted by a Mature Minor Expert Panel, receiving input on the issue of mature minor access to MAiD from health specialists, provincial and territorial child and youth advocates, medical practitioners, academics, researchers, mature minors, families, and ethicists (CCA, 2016).

1.5 MAiD and Ethical Challenges under Bill C-14

Many ethical issues were raised by the Carter decision and the subsequent legislative changes under Bill C-14 regarding the populations who met eligibility criteria. This section will discuss the principal ethical issues which emerged from the Carter decision.

1.5.1 Does MAiD Devalue the Sanctity of Life?

One aspect of the moral debate on MAiD is whether a blanket prohibition against physician-assisted death is necessary to uphold the sanctity of life. In *Carter*, the majority establish a connection between a prohibition on MAiD and preserving the sanctity of life. They argue that section 241 (b) of the Criminal Code is grounded in the state interest in protecting life and avoiding its depreciation, and is a significant part of the state's conception of the sanctity of life (*Rodriguez v. BC*, 1993, p 521h). Reflected in their briefs submitted as evidence to the Special Joint Committee on Physician Assisted Dying, religious organizations have argued that the practice of MAiD devalues life. For instance, the Canadian Conference of Catholic Bishops claim that their "Church clearly teaches ... that life is a sacred gift to be defended and protected..." (1). They therefore argue that when the state permits suicide as a medical procedure, this constitutes an indifference to the demeaning and devaluing of human life (Canadian Conference of Catholic Bishops, pp 1–2). Similarly, MAiD is not supported or encouraged in the Islamic faith on the basis that the Quran states the significance of saving life in 5:32: "Whoever saves (a life) – it is as if they had saved humanity entirely" (The Canadian Council of Imams, p 3). The Canadian Council of Imams therefore argues that life is sacred, and that cases where patients desire to end their lives due to grievous suffering must be met with prayer to relieve suffering, comfort, and the best possible care (The Canadian Council of Imams, p 3).

Yet under a different conception of the sanctity-of-life principle, respecting the right to life may entail respecting a right to a quality of life. The majority in *Rodriguez* also claimed that there are narrow exceptions to the sanctity of life principle to uphold personal autonomy and dignity (*Rodriguez v. BC*, 1993, p 512a). The SCC's claim is reflected in the position of the United Church of Canada, where they claim that believing in the sanctity of life does not mean that any attempt to end life must be prevented, as both life and death are part of the whole created order: "In life, in death, in life beyond death, God is with us" (The United Church of Canada, pp 1–2). This interpretation of the sanctity of life allows for a different conception of the right to life to include a right to a quality of life (*Carter v. Canada*, 2015, par. 59). In his dissent in *Rodriguez*, Supreme Court of Canada justice Cory argued that the right to die with dignity should be protected by s. 7 as much as any other aspect of the right to life because dying is an integral part of living (*Rodriguez v. BC*, 1993, p 526d–e). The trial judge in *Carter*, and later the Supreme Court of Canada found that an absolute prohibition on MAiD engaged the right to life, by creating a "duty to live" rather than a "right to life," and reasoned that a profound respect for human life which underlies s. 7 of the Charter also

encompasses life, liberty, and security of the person during the passage to death (Carter v. Canada, 2015, par. 57, 63).

A related argument is that the prohibition on physician-assisted dying does not uphold a sanctity-of-life principle in all cases, because it has the “effect of forcing some individuals to take their own lives prematurely, for fear that they would be incapable of doing so when they reached the point where suffering was intolerable” (Carter v. Canada, 2015, par. 57). In a statement, Gloria Taylor describes her wish to receive MAiD is for the purpose of extending her life as much as possible while she has a quality of life. She states:

I know that I am dying, but I am far from depressed ... there is still a lot of good in my life ... that bring[s] me extreme joy ... but I do not want to live a life without quality. There will come a point when I will know that enough is enough. ... When that time comes, I want to be able to call my family together, tell them of my decision, say a dignified good-bye and obtain final closure – for me and for them. My present quality of life is impaired by the fact that I am unable to say for certain that I will have the right to ask for physician-assisted dying when that “enough is enough” moment arrives. (Carter v. Canada, 2015, par. 12)

She further claimed that a prohibition on MAiD left her with a choice between taking her life prematurely while she is still physically capable and giving up control over the manner and timing of her death (Carter v. Canada, 2015, par. 13). On the basis of this choice, the plaintiffs in Carter argued that Taylor and others in her position experience a shortened lifespan by taking steps to end their lives “sooner than they would feel it necessary to do if they were able to receive assistance” (Carter v. Canada, 2012, par. 1325).

1.5.2 Can Safeguards Protect Vulnerable Persons?

In *Rodriguez v. BC* (1993), the Supreme Court of Canada ruled that the prohibition on physician-assisted dying relates to the state’s interest in protecting vulnerable persons, and that this reflects fundamental values in Canadian society (Rodriguez v. BC, 1993, p 522e). The Supreme Court of Canada likewise determined that the impugned legislation is aimed at the protection of vulnerable persons without a rational and considered desire for death who may be induced to commit suicide in a moment of weakness. Risks for the vulnerable may include being unable to communicate their refusal of the procedure, being unable to make competent value judgments, as well as errors in assessing capacity, ambivalence, and misdiagnosis (Carter v. Canada, 2015, par. 114). Factors contributing to

vulnerability may include cognitive impairment, depression or other mental illness, coercion, undue influence, psychological or emotional manipulation, and systemic prejudice against the elderly or people with disabilities (Carter v. Canada, 2015, par. 114).

Another aspect of the moral debate on MAiD is the issue of whether concerns for vulnerability can be addressed through strong safeguards and oversights. In their paper on “Rodriguez Redux,” Jocelyn Downie and Simone Bern argue that evidence has emerged since Rodriguez suggesting that crafting permissive legislation can protect the vulnerable (36). They point out that many patients who choose to obtain the prescription ultimately choose not to use it, and that those who access aid in dying are generally not members of the vulnerable groups requiring protection that were identified by the SCC majority in Rodriguez (36).

In Carter, the attorney general of Canada under Stephen Harper’s Conservative government argued that a blanket prohibition may be necessary to protect vulnerable persons because vulnerability cannot be straightforwardly identified. Although the elderly and disabled are frequently mentioned by the SCC as examples of vulnerable persons with respect to MAiD, “every person is potentially vulnerable” from a legislative perspective (Carter v. Canada, 2015, par. 87). Canada argued that with no reliable way to identify those who are vulnerable and those who are not, a blanket prohibition is needed to protect vulnerable persons from being induced to commit suicide at a moment of weakness (Carter v. Canada, 2015, par. 86, 114). Yet the trial judge ruled that evidence on comparable assessment processes in end-of-life medical decision-making in Canada suggests that vulnerability can be assessed on an individual basis, “using procedures that physicians apply in their assessments of informed consent and decisional capacity in the context of medical decision-making more generally” (Carter v. Canada, 2015, par. 115).

1.5.3 Equality and Persons with Disabilities

One important group of potentially vulnerable people is those with a disability, who some experts argue could experience discrimination as a result of decriminalizing MAiD. In particular there is a concern that clinicians or family will mistakenly evaluate that a patient’s life is not worth living by underestimating their quality of life or by overestimating their suffering or the difficulty of living with some types of disability (Carter v. Canada, 2012, par. 194, 807). In part, this concern results from the observation that persons with disabilities experience marginalization in Canadian society, and that this marginalization could affect their experience with end of life care (Carter v. Canada, 2012, par. 194). In fact, this marginalization can occur at an unconscious level due to institutional culture, and

patient dependency on clinicians for knowledge and care (Carter v. Canada, 2012, par. 808). In evidence submitted to the courts, Dr. Catherine Frazee argues that clinicians regularly steer patients with disabilities toward “do not resuscitate” (DNR) orders or prematurely to “comfort care” because they assume they “lean ... towards death at a sharper angle than the acutely ill – but otherwise non-disabled – patient[s]” (Carter v. Canada, 2012, par. 811).

In addition to putting patients with disabilities at risk of harm as the result of discrimination, Dr. Frazee argued that support for physician-assisted dying could contribute to public prejudice and stereotypes about disability, including a devaluation of the lives of disabled people (Carter v. Canada, 2012, par. 850). In particular, she asserts that discourse describing dignity as reliant on physical autonomy does not reflect the experience of the disability community; who perceive the relationship between dignity and physical autonomy as subjective and highly variable (Carter v. Canada, 2012, par. 850). Her concerns are exemplified in representations of a loss of dignity with a loss of control of bodily fluids, loss of mobility, and diminished capacity for independent self-care (Carter v. Canada, 2012, par. 850). This association of disability with “pain, sickness, frailty, incapacity, dehumanization, and poor quality of life” (Carter v. Canada, 2012, par. 848) could reinforce the idea that it is better to be dead than disabled – an ableist perception that is deeply embedded in our social consciousness (Carter v. Canada, 2012, par. 848).

Despite these concerns that decriminalizing physician-assisted dying could pose a risk to persons with disabilities, some experts argued that the option of physician-assisted dying is autonomy-promoting. In Carter the SCC state that some people in the disability community take the view that MAiD allows for control over the manner of one’s death, and it therefore respects, rather than threatens, the autonomy and dignity of disabled persons (Carter v. Canada, 2015, par. 10). Moreover, as was argued as a s. 15 claim in Rodriguez and Carter (see pp 2–3, 5), a blanket prohibition on physician-assisted suicide can create an inequality which limits the self-determination and individual autonomy of persons with disabilities. After all, the prohibition deprives persons who are physically unable to take their lives of the right to choose suicide, a fundamental decision regarding their lives and persons (Rodriguez v. BC, 1993, p 524j). Thus, concerns for vulnerability raise equality challenges. Criticism that safeguarding under Bill C-14 disadvantages the disabled by devaluing the lives of disabled people is met with the criticism that prohibiting MAiD disadvantages the disabled due to public prejudice and stereotypes, which violates their autonomy.

1.5.4 Are Physicians Who Conscientiously Object to MAiD Obligated to Refer Patients?

While much of the ethical debate on MAiD surrounds the issue of protecting the life and autonomy of vulnerable patients, there is also debate about the clinician’s role as a MAiD provider. Some clinicians were supportive of decriminalizing MAiD, believing that the legal change corresponds with a natural extension of patient autonomy (Carter v. Canada, 2015, par. 10). Other physicians, however, were concerned that decriminalizing MAiD violated core principles of medical ethics (Carter v. Canada, 2015, par. 10) or showed a lack of respect for their own personal conscience (Carter v. Canada, 2015, par. 130–131). Cases where physicians conscientiously object to providing MAiD create an issue of reconciling the rights of physicians while ensuring access to MAiD for eligible patients (Canadian Medical Association, 3). In Carter, the SCC heard from various organizations that expressed concern that physicians who conscientiously object to medical assistance in dying on moral grounds may be obligated to provide physician-assisted dying because they have a duty to act in their patients’ best interests (Carter v. Canada, 2015, par. 130). In response, the SCC declared that the Charter rights of patients and physicians must be reconciled (Carter v. Canada, 2015, par. 132).

A particular issue is whether physicians who conscientiously object have an obligation to refer patients to receive MAiD. In their brief to the Special Joint Committee on Physician Assisted Dying, the Canadian Medical Association stated that their position was that

physicians are not obligated to fulfill requests for assisted dying. This means that physicians who choose not to provide or participate in assisted dying are not required to provide it or participate in it or to refer the patient to a physician or a medical administrator who will provide assisted dying to the patient. (p 1)

Yet in a CMA member report on MAiD, some physicians claimed that “conscientious objectors should not be absolved of duties to communicate with [MAiD providers] ... [and that a] failure to refer ... patients ... to an appropriate physician is inappropriate and unacceptable” (3). In 2018, the Ontario Superior Court ruled on the issue of conscientious objection and effective referral in *The Christian Medical and Dental Society of Canada v. The College of Physicians and Surgeons of Ontario*. The court concluded that the requirement to provide an effective referral falls within reasonable limits justified in a free and democratic society under s. 1 of the Charter (*The Christian Medical and Dental Society of Canada v. The College of Physicians and Surgeons of Ontario*, 2018).

1.5.5 Is Decriminalizing MAiD a Slippery Slope to Decriminalizing Homicide?

Part of the ethical argument to decriminalize MAiD is that to obtain death with dignity, there is no moral difference between physician-assisted death and permissible end of life practices. In *Carter*, the trial judge found that the “preponderance of the evidence from ethicists is that there is no ethical distinction between physician-assisted death and other end-of-life practices whose outcome is highly likely to be death” (*Carter v. Canada*, 2015, par. 23), for instance, withholding or withdrawing life-sustaining treatment, voluntary stopping of eating and drinking (VSED), or administering palliative sedation. Collapsing these distinctions raises the concern that more moral distinctions will collapse, and Canada will descend a slippery slope to condoning murder (*Carter v. Canada*, 2015, par. 120). Yet the SCC concurred with the trial judge, who rejected this argument after an exhaustive review of the evidence (*Carter v. Canada*, 2015, par. 23). Arguments that permitting physician-assisted death risks a slippery slope relied on anecdotes of controversial cases abroad (*Carter v. Canada*, 2015, par. 23). Not only could these anecdotes be countered by anecdotal examples of systems that work well, the SCC stated that their ruling should not be informed by competing anecdotes, but by the evidence (*Carter v. Canada*, 2015, par. 23).

In reviewing the principal ethical issues emerging from *Carter v. Canada* and Bill C-14, there are a number of themes. One theme is professional duty, as challenging questions about the rights of patients must be reconciled with the professional rights of physicians to conscientiously object to providing MAiD. Personal conscience may raise concerns about MAiD and the sanctity of life, where beliefs that MAiD violates the sanctity of life by shortening life conflict with beliefs that MAiD lengthens the duration of life by preventing persons from committing suicide before their suffering becomes intolerable, and that the right to life includes life during the passage to death.

A central theme lies in determining whether safeguarding can protect vulnerable persons rather than an absolute prohibition. If it can, what is the appropriate degree of safeguarding which balances patient autonomy with their welfare, particularly in ensuring that the patient is capable and can communicate their informed consent. In determining the appropriate balance of safeguarding, the issue of equality arises. This is exemplified with MAiD and disability. Permitting MAiD risks safeguards which disadvantage the disabled by ignoring or perpetuating public prejudice and stereotypes about disability which devalue the lives of disabled people. Yet an absolute prohibition also risks disadvantaging the disabled by ignoring or perpetuating prejudice and stereotyping about disability, which limit their autonomy. These challenging questions about vulnerability and equality

are also relevant to other end-of-life decisions such as consenting to withdrawing or withholding life-sustaining treatment, VSED, and palliative sedation, raising the issue of whether prohibiting MAiD risks treating patients inconsistently. This issue of consistency is also applied to patient eligibility, asking whether access to MAiD should be extended to populations currently excluded under Bill C-14. This work now turns to analyzing ethical issues surrounding the eligibility of the three populations which were independently reviewed under the mandate of Bill C-14: mental illness as a sole underlying condition, advance directives, and mature minors.

1.6 Issues for Independent Review under Bill C-14

All three issues for independent review present difficulties because uncertainties surrounding the decision-making capacity of patients threaten to undermine their autonomy, leaving them vulnerable despite the existing safeguards. In the case of mental illness as a sole underlying condition, there is disagreement on whether a mental health condition can meet the criteria under Bill C-14, including the requirement that a patient’s natural death be “reasonably foreseeable,” their condition “incurable,” and their suffering “irremediable.” Further, there is uncertainty regarding the impact of a mental disorder on a patient’s legal capacity to request and consent to MAiD (Council of Canadian Academies, 2018, p 3). On the issue of advance directives, there is uncertainty regarding whether a person who makes a request desires the procedure at the time MAiD is provided, given the loss of decision-making capacity (Council of Canadian Academies, 2018, p 34). Lastly, on the issue of mature minors there is disagreement on whether mature minors can autonomously provide consent for MAiD at such a young age. These issues for independent review will be discussed in more detail in the following sections (1.5.1–1.5.3).

1.6.1 Mental Illness as a Sole Underlying Condition

On the issue of mental health as a sole underlying condition, the Special Joint Committee on Physician Assisted Dying⁴ asserts that the debate is not on whether patients ought to be excluded for having a mental health condition. For example, patients suffering from an aggressive form of cancer that meets the criteria for MAiD who also have a mental illness would not be excluded from eligibility on the basis of their mental illness. The Special Joint Committee argues that “the difficulty surrounding [situations where a patient has a mental health condition] is not a justification to

⁴ A committee with representation from the House of Commons and Senate mandated to study and make recommendations on options for a legislative response to Carter.

discriminate against affected individuals by denying them access to MAiD” (Ogilvie, Oliphant et al., p 14). Thus, they recommend:

Recommendation 3: That individuals not be excluded from eligibility for medical assistance in dying based on the fact that they have a psychiatric condition (Ogilvie, Oliphant et al., p 15).

Instead, the focus of the outstanding issue is on whether patients should be eligible for MAiD where there is a request solely on the basis of a mental health condition. There is disagreement on whether a mental health condition can meet certain eligibility criteria under Bill C-14, including the natural death of the patient being “reasonably foreseeable,” their condition “incurable,” and their suffering “irremediable.”⁵ Examining the issue, the Special Joint Committee on Physician Assisted Dying recommended that psychological suffering be included as a criterion for eligibility (Ogilvie, Oliphant et al., p 15).

Recommendation 4: That physical or psychological suffering that is enduring and intolerable to the person in the circumstances of his or her condition should be recognized as a criterion to access medical assistance in dying. (Ogilvie, Oliphant, et al., p 15)

Benoît Pelletier, a member of the External Panel and an expert in constitutional law, noted that the External Panel identified greater support from Canadians for MAiD in the context of a physical illness than a mental one (Ogilvie, Oliphant et al., p 13). Responses to the survey by the External Panel on Options for a Legislative Response to *Carter v. Canada* found opposition from 54% of the open public and 48% of the representative sample (who selected 1 or 2 on the scale of agreement) in Eligibility Scenario #4 (Chochinov, Frazee, Pelletier, p 33), where participants were given the following situation:

Imagine that you have suffered from a mental health condition for much of your life. Your condition has interfered with your ability to hold down steady work and has put a strain on your relationships. You have tried many treatments, most of which did not help or

⁵ Some psychiatrists argue that ‘irremediable’ cannot simply mean incurable, on the premise that despite many psychiatric and medical conditions being chronic and not curable, they can be remediated or improved (Ogilvie, Oliphant et al., 2016, p 13). Likewise, some argue that intolerable suffering does not equate to irremediable suffering (Ogilvie, Oliphant et al., 2016, p 14). Recognizing concerns that patients may be vulnerable to the impact of the social determinants of health, there is always potential for a mental illness to be remediable within a clinical recovery-based environment where recovery-based treatment is delivered (Ogilvie, Oliphant et al., 2016, p 13). Conversely, while there is always a potential for a person’s mental illness to be remediable, patients are not required to undertake treatments that are not acceptable to them in order for their condition to be considered irremediable (Ogilvie, Oliphant et al., 2016, p 14).

caused side effects that made you want to quit. You feel frustrated and hopeless about your future. Despite excellent care, you are considering ending your life, but you're afraid to try by yourself in case you don't succeed and make things worse. (Chochinov, Frazee, Pelletier, p 32)

Opposition (1 or 2 on the scale of agreement) increased in variants of the scenarios. One is where, despite one's worsened condition, a change in medication may improve one's situation (68% of open public, 66% of representative sample) (Chochinov, Frazee, Pelletier, 34). The other is where one has "been in this frame of mind before and improved" (70% of the open public, 67% of the representative sample) (Chochinov, Frazee, Pelletier, p 35).

In spite of the overall public opposition (according to the survey), experts are divided on the issue of whether the Carter criteria ought to apply to psychiatric conditions. Professor Downie voiced support for including psychiatric conditions in eligibility criteria, arguing that excluding individuals based on mental illness would violate the Charter: "Physicians already routinely determine whether someone is competent, even when they have a mental illness ... [and that] the suffering that can accompany mental illness can be as excruciating as any suffering that can accompany physical illness" (Ogilvie, Oliphant et al, p 13). Professor Downie also offers thoughts on the term 'irremediable'. She claims that meeting the criteria of an irremediable medical condition should not require patients to undertake treatments that they find unacceptable (Ogilvie, Oliphant et al., p 13).

Meanwhile Dr. K. Sonu Gaind, president of the Canadian Psychiatric Association, argued that certain challenges need to be addressed before psychiatric conditions become part of the inclusion criteria. For instance, "careful consideration needs to be given about what ['irremediable'] means in the context of mental illness" (Ogilvie, Oliphant et al, p 13). Dr. Gaind suggests that 'irremediable' should not simply mean incurable, as treatments may be given to remediate or improve one's situation where one has an incurable condition (Ogilvie, Oliphant et al., p 13). Dr. Tarek Rajji, chief of geriatric psychiatry at the Centre for Addiction and Mental Health, likewise argues that suffering should not be assumed to be irremediable. He points to an opportunity to deliver recovery-based treatment in cases where one's death is not impending and inevitable. Further, recovery-based treatment may entail removing a patient from a poor environment in cases where they are impacted by social determinants of health – which may be the factors exacerbating one's suffering.

The Council of Canadian Academies report found a wide range of potential impacts and implications of eligibility for patients with a mental illness as a sole underlying condition, which may

vary according to the individual and mental disorder, and which presents many knowledge gaps (Council of Canadian Academies, 2018, p 193). The Expert Working Group on the issue of mental health as a sole underlying condition disagreed on a number of issues. In addition to the disagreements outlined above, the working group disagreed on how to balance the risk of ending life where the person's condition would have improved or where the person would have regained the desire to live, with the risk of forcing the person to continue living with intolerable suffering where their condition did not improve (Council of Canadian Academies, 2018, p 197). Moreover, there is disagreement on whether there is a valid and reliable method to distinguish whether the desire to die of a person requesting MAiD with a mental disorder as their sole underlying condition is a symptom of their mental disorder (Council of Canadian Academies, 2018, p 197). There is likewise uncertainty on whether there is a significant ethical distinction between capacity assessments for persons with a mental disorder in the context of refusal of life sustaining treatment and MAiD (Council of Canadian Academies, 2018, p 197). Another issue is whether there is a fundamental ethical distinction between cases where the person's natural death is reasonably foreseeable and those where there is no reasonably foreseeable natural death (Council of Canadian Academies, 2018, p 197).

1.6.2 Advance Directives

An advance directive serves as evidence of the patient's previously expressed capable wish(es) to be carried out by the substitute decision-maker (Buchanan and Brock, p 99), an agent authorized to give informed consent on behalf of an incapable patient with respect to the treatment (HCCA, 1996, s. 9). On the issue of advance directives, intuitions on how to best respect the autonomy of the patient conflict. Allowing advance directives for MAiD respects patient self-determination of not only present decisions, but decisions influencing "what is to happen in the future, when the person is no longer competent" (Buchanan and Brock, p 98). Still, when it comes to progressive conditions such as dementia and Alzheimer's disease, some experts argue that patients cannot predict future suffering – thus the directives are not fully informed. Concerns about prediction of future suffering are accompanied by evidence that terminally ill patients' desire to die fluctuates substantially over time, with predictor variables including depression, anxiety, shortness of breath, and sense of well-being (Chochinov et al., 1999, p 816).

Contemplating the issue of advance directives, the Special Joint Committee on Physician Assisted Dying presents three situations where an advance directive could be considered: (1) where a person's request has been accepted but the individual loses competence before MAiD takes place; (2) where a

person has been diagnosed with a grievous and irremediable condition but is not yet experiencing enduring and intolerable suffering; and (3) prior to diagnosis (Ogilvie, Oliphant et al., pp 21–22). The Special Joint Committee recommends that an advance request should be accepted in the first two situations, but not the third:

Recommendation 7: That the permission to use advance requests for medical assistance in dying be allowed any time after one is diagnosed with a condition that is reasonably likely to cause loss of competence or after a diagnosis of a grievous or irremediable condition but before the suffering becomes intolerable. An advance request may not, however, be made prior to being diagnosed with such a condition. The advance request is subject to the same procedural safeguards as those in place for contemporaneous requests. (Ogilvie, Oliphant et al., p 24)

This recommendation follows from an argument similar to that made by law professor Jocelyn Downie that advance requests allow MAiD to be undertaken before one's condition declines such that suffering is enduring and intolerable. Further, permitting advance requests for MAiD prevents suffering in cases where one is approved for the treatment but then loses competence. Lastly, allowing advance directives for MAiD prevents individuals from ending their lives earlier than they would otherwise in order to avoid losing competence before the suffering becomes intolerable (Ogilvie, Oliphant et al., 22).

Indeed, recommendation 7 from the Special Joint Committee on Physician Assisted Dying reflects public perception. In their consultations on physician-assisted dying, the External Panel on Options for a Legislative Response to *Carter v. Canada* found that responses both from their open public survey and from their survey of a representative sample of the public showed support for the option of MAiD in a number of scenarios involving a progressive condition. In Eligibility Scenario #3, participants were given the following situation:

Imagine that you have just been diagnosed with Alzheimer's. The disease will have a serious impact on your life and will worsen over time. You have discussed your prognosis extensively with your physician, and you have a clear understanding of what lies ahead for you. You are considering options available to you. (Chochinov, Frazee, Pelletier, p 28)

Respondents selected the extent of one's agreement or disagreement with being able to receive a physician's assistance to die in this scenario on a 1-to-5 scale, with 1 representing strong disagreement and 5 representing strong agreement. Responses slightly favoured the option for MAiD,

though they were highly polarized: 42% of the open public strongly agreed, while 37% strongly disagreed (Chochinov, Frazee, Pelletier, p 28). The representative sample showed more variance in the extent of their agreement, but overall demonstrated support for access to the treatment, with nearly 70% of respondents selecting between 3 and 5 (neutral to strongly agree) on the scale of agreement (Chochinov, Frazee, Pelletier, p 28).

In spite of public support for advance directives, some experts caution that patients are extremely vulnerable at the end of life and that permitting advance requests for MAiD could result in people receiving MAiD who do not have a desire to die at the time of provision. In their evidence to the Special Joint Committee on Physician Assisted Dying, the Alzheimer's Society argued that at the time a patient with dementia receives MAiD their values and beliefs may not reflect those expressed in the advance request. They affirm that a diagnosis of dementia does not render someone immediately incapable and that, due to the progressive nature of dementia, specific skills will be lost during the course of the disease, including the capacity to consent to treatment, including MAiD (Canada, Parliament, 2016, web). During this time, given the progressive nature of dementia, wishes, values, and beliefs may change, skills are lost, and the ability to make decisions is greatly reduced (Canada, Parliament, 2016, web). Along with the observation that we cannot predict future suffering, the Alzheimer's Society expressed concern that there is potential for the patient's beliefs and values not to match those expressed in the advance request (Canada, Parliament, 2016, web). The Society concludes that incapable patients with dementia should not be permitted to access MAiD through an advance request (Canada, Parliament, 2016, web).

Other experts argue that permitting patients to make advance requests for MAiD could lead to manipulation and abuse. One concern is that if a patient becomes incompetent it will not be possible to verify if the advance request was made under duress (Ogilvie, Oliphant et al., p 23). Moreover, the patient's suffering may be misjudged in cases of dementia because of conditions included in their advance directive. The worry is that someone who is still enjoying life could end up dying by MAiD because he or she met the criteria related to suffering (e.g., recognizing family members) (Ogilvie, Oliphant et al., p 23). Dr. Jeff Blackmer of the Canadian Medical Association (CMA) described implementing advance directives as "incredibly complex and difficult, because it's very hard to capture all of the nuances and the specifics of a very complicated medical condition and intervention" (Ogilvie, Oliphant et al., p 23). The nuances and moral complexity surrounding autonomy and

capacity in dementia explain why, in C-14, the Canadian government put off a decision on advance directives for MAiD and called for further study.

The Council of Canadian Academies working group on the issue of advance requests considered a number of factors on whether to permit advance requests in addition to the benefits and risks outlined above. One consideration was whether advance requests for MAiD could be influenced by prior or anticipated experience of inaccessible and inadequate support to meet healthcare and social needs, or by a biased perception of their future quality of life (Council of Canadian Academies, 2018, p 173). Concerns about fluctuating desire to die given loss of capacity are supplemented by concerns of a patient's inability to communicate that they have changed their mind (Council of Canadian Academies, 2018, p 175). There is a risk that a patient receives MAiD as the result of third-party decision-makers incorrectly interpreting an advance request or the person's incapable behaviour (Council of Canadian Academies, 2018, p 175). Moreover, there was concern that waiving express consent immediately prior to the procedure could blur the distinction between voluntary and involuntary MAiD (Council of Canadian Academies, 2018, p 174).

There was disagreement among the working group members on whether potential safeguards could effectively mitigate to an acceptable level the risk that a patient without a rational and considered desire for death will in fact end up dead (Council of Canadian Academies, 2018, p 175). Potential safeguards included: optimizing clinical processes by providing education, training, and counselling and social work support on clinical and legal aspects of end of life care for patients, families, and health care providers; access to quality care and support; clarifying how existing safeguards such as informed consent and intolerable suffering are understood in the context of advance requests; and introducing safeguards which would narrow eligibility in cases of advance requests (Council of Canadian Academies, 2018, p 175). Criteria to narrow eligibility could include limiting circumstances where advance requests would be permitted (e.g., only in cases of irreversible unconsciousness), time limits on the validity of an advance request for MAiD, requiring expert consultation or review by a multidisciplinary committee in the assessment, specific guidance on the role of substitute decision makers (SDMs) in implementing an advance request for MAiD (Council of Canadian Academies, 2018, p 175). While narrowing eligibility may mitigate the risk that a patient without a rational and considered desire to die may end up dead, this may create the risk of excluding patients with such a rational and considered wish, leaving them to suffer or end their lives prematurely – the exact situation the Carter decision sought to avoid (Ogilvie, Oliphant et al., 2016, p 24).

1.6.3 Mature Minors

The mature minor issue predominantly centres on what the appropriate age of consent ought to be with respect to MAiD. Although Bill C-14 restricts eligibility to a specific age, 18 years or older, most Canadian provinces specify no age of consent with respect to treatment.⁶ Instead of specifying a minimum age, most provinces govern consent to treatment in accordance with a minor demonstration of capacity. The Special Joint Committee on Physician Assisted Dying addressed the particular case of mature minor eligibility as presenting conflicting considerations. Some expert witnesses to the Special Joint Committee on Physician Assisted Dying were concerned about the capacity of minors to understand the implications of the decision (Ogilvie, Oliphant et al., p 18). The incapability of mature minors could warrant them being part of the class of vulnerable persons that a ban on assisted suicide was meant to protect. Yet characterizing all minors as incapable does not recognize their developing decision-making capacity. The Special Joint Committee recognized that the Supreme Court stated in *AC v. Manitoba* that minors have a right “to a degree of decision-making autonomy that is reflective of their evolving intelligence and understanding” (2009, par. 69). Further, because children can suffer as much as any adult, the committee felt that it is difficult to justify an outright ban on access to MAiD (Ogilvie, Oliphant et al., p 18).

Responses to the survey by the External Panel on Options for a Legislative Response to *Carter v. Canada* demonstrated variance from the open public and the representative sample. Eligibility Scenario 1 states:

Imagine that you have a serious life-threatening illness. Your doctor has told you that the disease has advanced, and that you likely only have months to live. Despite not having any significant discomfort, you are not interested in going through a long and lingering death. You are considering your end-of-life options.

In a variation of this scenario where one received the diagnosis at age 16, has a full and complete understanding of one’s condition, and wishes to die, 46% of the open-public respondents expressed opposition (selecting 1 or 2 on the scale of agreement) compared to only 34% of the representative sample (Chochinov, Frazee, Pelletier, p 21). Yet opposition increased significantly where mature minor status intersected with mental health as a sole underlying condition. In a variation of Eligibility Scenario 4 (Chochinov, Frazee, Pelletier, p 23) where one is 17 years old, has a full and complete

⁶ Quebec and New Brunswick do specify an age of consent to medical treatment, at 14 and 16 respectively. This includes refusing or withdrawing consent to receive life-sustaining treatment.

understanding of their condition, and wishes to die, 70% of the open-public respondents and 67% of the representative sample respondents expressed disagreement (selecting 1 or 2 on the scale of agreement) (Chochinov, Frazee, Pelletier, p 36).

1.7 Eligibility Challenges post–Bill C-14

1.7.1 *Lamb and British Columbia Civil Liberties Association v. Canada (Attorney General)*

On June 27, 2016, Julia Lamb and the British Columbia Civil Liberties Association launched a civil claim to challenge the constitutional validity of federal legislation governing MAiD in Canada (Health Law Institute Dalhousie University, NDA, web). Lamb was concerned that her condition⁷ would decline such that her symptoms would cause unbearable suffering, and worried that she would be ineligible for MAiD based on her natural death not being reasonably foreseeable, her not being in an advanced state of irreversible decline in capability, and her illness not being found to be incurable (*Lamb and British Columbia Civil Liberties Association v. Canada (Attorney General)*, 2017, par. 34–36). She therefore argued that eligibility under the federal law is too restrictive.

⁷ Julia Lamb was diagnosed with Spinal Muscular Atrophy (SMA), Type 2 at 16 months, a hereditary disease that causes weakness and wasting of the voluntary muscles leading over time to areflexia, overall muscle weakness, loss of function, respiratory distress, fasciculations of the tongue, and difficulty swallowing (*Lamb and British Columbia Civil Liberties Association v. Canada (Attorney General)*, 2016, par. 6, 11). Most individuals with SMA Type 2 live well into adulthood with a reduced life expectancy (*Lamb and British Columbia Civil Liberties Association v. Canada (Attorney General)*, 2016, par. 10). She developed scoliosis and experienced complications of surgery to treat her scoliosis at age 7, where one of her lungs collapsed, resulting in severe back pain (*Lamb and British Columbia Civil Liberties Association v. Canada (Attorney General)*, 2016, par. 11, 22). In 2016 her lung capacity was at 30%, causing excruciating headaches and requiring non-invasive ventilation at night (*Lamb and British Columbia Civil Liberties Association v. Canada (Attorney General)*, 2016, par. 26–27). She developed osteoporosis in her adolescence, which has progressed to become severe, has resulted in her being unable to stand, and has caused numerous broken and fractured bones from falls (*Lamb and British Columbia Civil Liberties Association v. Canada (Attorney General)*, 2016, par. 12, 29). Lamb is unable to move or bend her legs, cannot bend her hips, and has limited mobility in her arms, causing pain from muscle contractures (*Lamb and British Columbia Civil Liberties Association v. Canada (Attorney General)*, 2016, par. 18, 22). She requires a wheelchair for mobility and assistance for all activities of daily living (ADLs) including bathing, dressing, toileting and preparing meals (*Lamb and British Columbia Civil Liberties Association v. Canada (Attorney General)*, 2016, par. 11, 23). She requires assistance to be turned in her bed to avert developing bed-sores (*Lamb and British Columbia Civil Liberties Association v. Canada (Attorney General)*, 2016, par. 16). More recently, she had experienced decreased mobility, began to suffer repeated respiratory infections, and is experiencing increased difficulty with swallowing (*Lamb and British Columbia Civil Liberties Association v. Canada (Attorney General)*, 2016, par. 15, 24–25). Julia expects that her condition will decline further over time where she may require a permanent tracheotomy, lose the use of her hands, and lose the ability to eat, requiring a feeding tube (*Lamb and British Columbia Civil Liberties Association v. Canada (Attorney General)*, 2016, par. 30–33).

The case was adjourned on September 18, 2019 due to a finding in expert witness evidence that Lamb would likely be found eligible for MAiD if she intended to discontinue and refuse treatment⁸ in the event that she developed a chest infection as a result of stopping using her BiPaP machine (BC Civil Liberties Association, 2019, web). This conclusion did not result in a judgment on whether the law was constitutional, but did advance understanding of the interpretation of what constitutes a reasonably foreseeable natural death (Health Law Institute Dalhousie University, NDA, web).

1.7.2 *Truchon c. Procureur général du Canada*

In 2019, four years after MAiD was legalized, applicants Jean Truchon and Nicole Gladu challenged the constitutional validity of the eligibility requirement that a person's natural death be reasonably foreseeable (outlined in s. 241.2(2)(d) of Bill C-14) and the requirement that a person be at the end of life (outlined in subsection 3 of the first paragraph of s. 26 of the Act respecting end-of-life care) (Truchon c. Procureur général du Canada, 2019, par. 3–5). Both applicants requested MAiD and were found ineligible based on the fact that they did not have a reasonably foreseeable natural death, although they otherwise qualified as having a grievous and irremediable medical condition (Truchon c. Procureur général du Canada, 2019, par. 498).⁹ Given that they did not qualify for MAiD, the court

⁸ Lamb would have to discontinue use of her BiPaP machine, a form of non-invasive ventilation, and refuse treatment for the infection.

⁹ Jean Truchon was 51 years old and had suffered from spastic cerebral palsy with tripareisis since birth, which resulted in complete paralysis with the exception of his left arm (Truchon c. Procureur général du Canada, 2019, par. 17). Truchon was capable of performing certain everyday tasks and was mobile in a wheelchair, but was diagnosed in 2012 with severe spinal stenosis and myelomalacia, a degenerative condition with no hope of improvement, which led to the paralysis of his remaining limb and for which no surgical or pharmacological treatment exists (Truchon c. Procureur général du Canada, 2019, par. 17, 23–24). Truchon's condition caused significant enduring and constant pain in the arms and neck, including intense burning sensations and painful spasms, along with psychological suffering, including a depressive episode (Truchon c. Procureur général du Canada, 2019, par. 25–26).

established strong evidence that if the requirement for a reasonably foreseeable death is upheld, Gladu's intention would be to travel to Switzerland to die and that Truchon's intention would be to voluntarily die of hunger and thirst (Truchon c. Procureur général du Canada, 2019, par. 520). The applicants argued that the reasonably foreseeable natural death/end of life eligibility requirements infringe upon their s. 7 right to life, liberty, and security of the person and their s. 15 right to equality under the Canadian Charter of Rights and Freedoms (Truchon c. Procureur général du Canada, 2019, par. 6). Further, the applicants argued that the end of life/reasonably foreseeable natural death requirement violates principles set out in *Carter v. Canada* (2015) such that rights granted by the Carter decisions to obtain MAiD were removed from them (Truchon c. Procureur général du Canada, 2019, par. 7).

In its decision, the Quebec Superior Court declared the provisions to be constitutionally invalid (Truchon c. Procureur général du Canada, 2019, par. 12). Justice Baudouin found that the statutory requirement for a reasonably foreseeable natural death under s. 241.2(2)(d) of the Criminal Code and that of end of life under subsection 3 of the first paragraph of s. 26 of the Quebec legislation infringe upon the applicants' ss. 7 and 15 Charter rights, and that these infringements cannot be justified under s. 1 (Truchon c. Procureur général du Canada, 2019, par. 12). The decision first affirmed that the provisions are inconsistent in the Carter decision (Truchon c. Procureur général du Canada, 2019, par. 501). Further Justice Baudouin found that such statutory measures "deprive people with medical conditions similar to those of the applicants" of access to medical assistance in dying, which was granted by the Carter decision (Truchon c. Procureur général du Canada, 2019, par. 501). These judgments were based on the court's view that, rather than the proximity of death, respect for a person's wishes, the preservation of a person's dignity, and the alleviation of intolerable suffering

Nicole Gladu was 73 years old, and suffered from significant sequelae resulting from an acute paralyzing form of poliomyelitis she had suffered at the age of 4, including residual paralysis of the left side, and severe scoliosis caused by the gradual deformation of her spinal column. (Truchon c. Procureur général du Canada, 2019, par. 51). In 1992, Gladu was diagnosed with degenerative muscular post-polio syndrome, "a degenerative neurological disease characterized by general fatigue, gradual or sudden muscular weakness, and mobility-reducing muscle pain" (Truchon c. Procureur général du Canada, 2019, par. 56). In 1997, Gladu developed thrombophlebitis and a hiatal hernia (Truchon c. Procureur général du Canada, 2019, par. 56). Over time, she developed a severe case of osteoporosis, her spinal deformity worsened, and her thoracolumbar scoliosis caused a severe restrictive lung disease with nocturnal desaturation (lung capacity is reduced to approximately half a lung) (Truchon c. Procureur général du Canada, 2019, par. 57). In addition to challenges breathing, Gladu is in constant pain, her body cannot hold her up, and she also has difficulties eating due to her condition (Truchon c. Procureur général du Canada, 2019, par. 57, 60). Further, due to her deteriorating condition, and because of the death of her mother she suffered from two depressions (Truchon c. Procureur général du Canada, 2019, par. 56).

associated with a grievous and irremediable medical condition are the basis for the ruling in *Carter v. Canada* (2015) (Truchon c. Procureur général du Canada, 2019, par. 497). Moreover, in drawing parallels with other end-of-life decisions, Justice Baudouin noted many situations where patients who are neither dying nor in the terminal stage of life refuse life-sustaining treatment (Truchon c. Procureur général du Canada, 2019, par. 500).

Justice Baudouin then addressed the arguments made by the applicants that the reasonably-foreseeable-natural-death requirement violates s. 7 and s. 15 of the Charter, and that the end-of-life requirement violates s. 15.¹⁰ In the s. 7 analysis, Baudouin establishes that the reasonably-foreseeable-natural-death requirement exposes individuals to a heightened risk of death, due to the possibility that forced prolongation of life and accompanying suffering may cause some patients to become inclined to end their lives prematurely in a degrading and violent manner before reaching a state of “mortal agony” or loss of dignity (Truchon c. Procureur général du Canada, 2019, par. 521–522). Further, the reasonably-foreseeable-natural-death requirement engages s. 7 rights to liberty and security by directly interfering with one’s physical integrity; depriving one of the freedom and autonomy to make fundamental medical decisions affecting one’s own body, and depriving one of dignity and forcing suffering (Truchon c. Procureur général du Canada, 2019, par. 528–534).

In seeking to protect the vulnerable who may be induced to end their lives in a moment of weakness, the statutory provisions have a similar purpose to that given in *Carter v. Canada* (2015) and are therefore not arbitrary (Truchon c. Procureur général du Canada, 2019, par. 562–567). Yet Justice Baudouin found the provisions to be overbroad, as the state-imposed limitations, characterized as a general precautionary principle, exceed the purpose to the extent that they have “no real connection to the object of protecting vulnerable persons” (Truchon c. Procureur général du Canada, 2019, par. 572–574). Due to the serious “prejudicial effects on the applicants’ life, liberty, and security,” and the fact that the requirement creates a state-imposed obligation to live (precisely what the SCC wished to avoid in the *Carter* decision) the provisions were also found to be grossly disproportionate to their purpose (Truchon c. Procureur général du Canada, 2019, par. 582–583).

The provisions were then analyzed to determine whether they are saved by s. 1 of the Charter (i.e. the premise that rights under the Charter are guaranteed to such reasonable limits as prescribed by law and can be justified in a free and democratic society). Through applying the *Oakes* test, a

¹⁰ The Court did not examine the end of life provision in terms of section 7 (Truchon c. Procureur général du Canada, 2019, par. 733).

constitutional test to determine whether a limit on a Charter right is “reasonable” and “demonstrably justified” under s. 1 of the Charter (Department of Justice, web). Justice Baudouin determined that the limit on ss. 7 and 15 were prescribed by law, that the object of the provision (i.e., protecting the vulnerable¹¹) was pressing and substantial (Truchon c. Procureur général du Canada, 2019, par. 582–583). The application of the Oakes test also determined a rational connection between the limit on Charter rights and the purpose of the provisions (Truchon c. Procureur général du Canada, 2019, par. 615). Yet the test failed as the provisions were not confined to what was reasonably necessary and thus did not minimally impair rights, and the negative effects of the provision outweighed the expected benefits to society as a whole (Truchon c. Procureur général du Canada, 2019, par. 617, 631).

Baudouin lastly determined that provisions engaged s. 15 of the Charter (Truchon c. Procureur général du Canada, 2019, par. 683, 708). The court accepted the applicants’ arguments that the provisions create a distinction based on physical disability as an enumerated ground in two respects. One distinction is on the basis of the foreseeability of natural death, the other is on the basis of the ability to end one’s life unassisted (Truchon c. Procureur général du Canada, 2019, par. 652, 665). Moreover in the context of paternalistic stereotypes/prejudices that the vulnerability of the disabled compromises their autonomy and that they cannot consent fully to MAiD (Truchon c. Procureur général du Canada, 2019, par. 680–681), these distinctions based on physical disability were found to perpetuate disadvantage, as the provisions did not “consider the applicants’ personal circumstances, characteristics, and actual needs” in order to respect their value as human beings compared to those recognized with the right to access MAiD (Truchon c. Procureur général du Canada, 2019, par. 673–674). The courts conclusions that s. 7 violations are not minimally impairing and are therefore not saved by s. 1 is also applied to the s. 15 violations of both provisions, which likewise was not minimally impairing (Truchon c. Procureur général du Canada, 2019, par. 685, 731).

1.7.3 Bill C-7: A New Frontier of MAiD Assessments and Provision

Neither the federal government nor the government of Quebec chose to appeal the Truchon decision (Health Canada, 2020, p 41). On March 17, 2021 Bill C-7 received royal assent, amending the Criminal Code to comply with the Truchon decision by removing the eligibility requirement for a reasonably foreseeable natural death (Bill C-7, 1(1)). Further, a sunset clause was added, which

¹¹ The object of subsection 3 of the first paragraph of s. 26 of the Act respecting end-of-life care is end of life and the recognition of dignity and autonomy (Truchon c. Procureur général du Canada, 2019, par. 725).

expands MAiD eligibility to patient with mental illness as a sole underlying condition on March 17, 2023, two years after the date Bill C-7 received royal assent (ss. 1(2.1), 6).

Amendments to safeguards were also made which effectively created two streams of safeguarding for eligibility, distinguished based on whether the person's natural death has become reasonably foreseeable. Regardless of whether a patient's natural death has become reasonably foreseeable, only one independent witness is required for the written request (Bill C-7, ss. 1(4), 1(7,3.1,c)), and a paid personal or health care worker can act as an independent witness unless they are the assessing or providing physician (Bill C-7, s. 1(8)). Further, all necessary means must be taken to provide reliable understanding and communication where the person has difficulty communicating (Bill C-7, ss. 1(5,g), 1(7(3.1(j))))).

Where a natural death has become reasonably foreseeable, the requirement for final consent is waived in circumstances where persons approved for MAiD risk losing the capacity to consent before their scheduled date for MAiD, and they have a written agreement with their practitioner (Bill C-7, s.1(7(3.2))). In such cases, the incapable person must not demonstrate refusal or resistance to the procedure by words, sounds, or gestures, or else they can no longer receive MAiD on the basis of the consent given in the written agreement (Bill C-7, ss. 1(7(3.2(c))), 1(7(3.4))). This is qualified by the statement that involuntary responses to contact are not considered a demonstration of refusal or resistance (Bill C-7, s. 1(7(3.3))). An agreement in writing can also be made between the person and the providing physician in cases of self-administration. In such cases the written agreement allows the providing physician to be present for the patient's self-administration, and to provide the patient with euthanasia in the event that the patient does not die within the period specified in the agreement and loses their capacity to provide consent to euthanasia (Bill C-7, s. 1(7(3.5))).

In cases where a natural death has not become reasonably foreseeable, safeguards were added to ensure adequate time and expertise are devoted to the assessment process. These safeguards include a requirement for the assessors to consult with a physician or nurse practitioner with expertise in the condition that is causing the patient's suffering if neither assessor has such expertise; that the person is informed of means to relieve suffering which include (where appropriate) counselling services, mental health and disability support services, community services, and palliative care; that the two independent medical or nurse practitioners inform the person and discuss with them the reasonable and available means to relieve the person's suffering and agree that the person has given such means serious thought; a 90 clear day reflection period between the date of the first assessment and the day

of provision (which may be shortened if loss of capacity to provide consent is imminent); and a requirement for express consent immediately before the provision (Bill C-7, s. 1(7(3.1))).

C-7–enhanced reporting requirements for national monitoring and data collection, requiring MAiD assessors, any person with responsibility to carry out preliminary assessments, and pharmacists and pharmacy technicians who dispense a substance in connection with the provision of MAiD to complete federal reporting (Bill C-7, s. 3 (1)). The Bill lastly requires two reviews to be undertaken. One is an expert independent review on recommended protocols, guidance, and safeguards to apply to MAiD requests by persons who have a mental illness (Bill C-7, s. 3.1). The other is a Joint Committee review by both Houses of Parliament on the statutory framework governing MAiD and its application to issues relating to mature minors, advance requests, mental illness, the state of palliative care in Canada and the protection of Canadians with disabilities (Bill C-7, s. 5).

1.8 Dissertation Structure

This dissertation aims to inform reflection, discussion, and principled determination on the issue of mature minor eligibility for MAiD, by analyzing four areas of inquiry surrounding our obligations regarding children's self-determination and child welfare. The first area of inquiry is explored in Chapter 2 and analyzes the values of autonomy and welfare (in terms of vulnerability) in the context of MAiD, focusing specifically on significant considerations in the child and adolescent population. The second area of inquiry considers the reflection of conflicting ethical duties to children's autonomy and welfare in statutory and common law. Chapter 3 provides an overview of the legal landscape empowering child and adolescent self-determination and protecting their well-being. Yet there are stronger legal duties to protect children's interests than those of adults, and we organize society such that children are treated differently in order to shield them as a vulnerable group (*AC v. Manitoba*, 2009; Council of Canadian Academies, 2018; United Nations Human Rights Office of the High Commissioner, 1989).

Chapter 4 gives a closer analysis of *AC v. Manitoba* (2009), a case of a 14-year-old Jehovah's Witness who received a life-saving blood transfusion against her will. The case balanced values of autonomy (through self-determination) and welfare, and determined that children have a legal right "to a degree of decision-making autonomy ... reflective of their evolving intelligence and understanding" (*AC v. Manitoba*, 2009). Based on this precedent, the chapter then affirms the s. 7 rights to life, liberty, and security of the person in the case of children. Moreover, adolescent claims to equality in s. 15 of the Charter will be discussed. Section 15 was assumed to be violated but was saved by s. 1 of the Charter in *Rodriguez v. BC* (1993), and s. 15 analysis was not given in *Carter v. Canada* (2015). Yet in the case of minors there are substantial equality issues lying in their differential treatment from adults and the disparity between MAiD and other treatments with respect to consent.¹²

The third area of inquiry analyzes MAiD for mature minors in terms of welfare considerations. Chapter 5 gives an overview of welfare in end-of-life decisions for infants, children, and adolescents, noting that the benefits of relief of suffering, dignity, and quality of life are weighed against the harm

¹² The reason mature minors present an outstanding issue is that, although Bill C-14 restricts eligibility to a specific age, 18 or older, most Canadian provinces specify no age of consent with respect to treatment. In fact, among the three provinces which identify mature minors according to a specific age (16 in New Brunswick, 16 in Newfoundland and Labrador at 16, and 14 in Quebec), none concur with the age of consent being 18 (Jackman and McRay, 1).

of shortening life. The chapter focuses particularly on infants, where decisions are determined completely on welfare considerations through projected clinical outcomes. The analysis demonstrates that a decision to receive MAiD may be motivated by welfare considerations where it is motivated by severe pain and suffering, a low quality of life, and an unwillingness to endure continued indignities. Specifically in cases of futility, the values of dignity, reducing suffering, and preserving quality of life overcome the presumption that prolonging life serves well-being. Further, the chapter reframes the concept of risk in such harm-benefit analysis from the question of whether one dies to questions of when and how, and what happens to a person until they die.

Finally, the fourth area of inquiry compares the mature minor decision to receive MAiD with other end-of-life decisions, including the choice to refuse life-sustaining treatment, asking whether there is a fundamental ethical distinction. In particular, Chapter 6 considers whether MAiD, as a life-and-death decision, is too “weighty” a decision for a mature minor to make. The chapter then characterizes this ethical distinction using the doctrine of double effect, which presumes that death is inherently harmful and that this harm impacts the informed-consent process. Based on this analysis, these factors support the following premise: refusing life-sustaining treatment, a choice to die where one could otherwise live, is a weightier decision than the decision to receive MAiD, a choice of how one dies where death is unavoidable. Thus a distinction permitting a minor to refuse life-sustaining treatment while refusing to allow minors to consent to MAiD treats minors inconsistently.

Based on these chapters, this dissertation argues that mature minors should be eligible to receive MAiD – that is, that MAiD should be calibrated according to maturity rather than age. This work makes two key arguments. One is that an age criterion to access MAiD is an unjustifiable act of age discrimination. Children who are otherwise eligible for MAiD suffer to the same extent as adults. By creating a situation where adults can end their suffering on their own terms while children cannot, Bill C-14 imposes disadvantages on children that are not imposed upon adults. The second is that the age criterion in Bill C-14 treats minors inconsistently. The law rightly permits mature minors to refuse life-sustaining treatment, for example a blood transfusion on religious grounds, yet prohibits them from consenting to MAiD. This legal inconsistency is also an ethical inconsistency: mature minors are able to choose to die when they could otherwise live, yet they are unable to control how they die when their death is unavoidable. Neither of these arguments is overcome by considerations of protecting the well-being of minors in cases of futility, where the value of prolonging life is outweighed by values of dignity, reducing suffering, and preserving quality of life.

Chapter 2

An Analysis of Mature Minor Autonomy and Vulnerability

2.1 Prologue

Chapter 1 provided some context on the legal decisions and legislative changes which led to the legalization of MAiD in Canada. In particular, the chapter reviewed the central legal arguments made by the plaintiffs and the SCC in *Carter v. Canada* against the constitutionality of ss. 14 and 241 (b) of the Criminal Code. In their ruling, the SCC framed Gloria Taylor’s request for the “legal right to die peacefully, at the time of [her] own choosing” (*Carter v. Canada*, 2015, par. 12) as a question of balancing the values of autonomy and dignity against the sanctity of life and the need to protect the vulnerable (*Carter v. Canada*, 2015, par. 2).

The SCC ultimately determined that these competing values can be balanced in permitting access to MAiD with adequate safeguarding. An important aspect of this analysis concerned whether a blanket prohibition on MAiD is necessary to protect the vulnerable, or whether a permissive model could protect the vulnerable through strong safeguards and oversights. In the context of MAiD, the SCC specifically considered vulnerability in terms of the heightened decisional risk that persons without a “rational and considered desire for death” will choose to die (*Carter v. Canada*, 2015, par. 114). Factors which may leave patients decisionally vulnerable include “cognitive impairment ... mental illness, coercion, undue influence, psychological or emotional manipulation, systemic prejudice (against the elderly or people with disabilities) ... and ambivalence or misdiagnosis” (*Carter v. Canada*, 2015, par. 114). The SCC agreed with the trial judge that “a permissive regime with properly designed and administered safeguards was capable of protecting vulnerable people from abuse and error,” and that vulnerability can be assessed on a case-by-case basis (*Carter v. Canada*, 2015, par. 116).

The safeguarding system introduced under Bill C-14 excludes mature minors from eligibility for MAiD, yet the question of mature minor eligibility raises a very similar moral issue to the adult context: the conflict between the values of autonomy and welfare. As developing agents, some children and adolescents are recognized to be capable of making health care decisions. Some experts argue that capable children with a grievous and irremediable medical condition should be permitted to access MAiD based on the right to liberty and the values of autonomy and dignity, much like in the

adult context. Further, the premise that children can experience the same degree of intolerable suffering as adults justifies access based on the right to security of the person. Yet there is concern that children and adolescents are not sufficiently capable to make decisions and cannot understand the implications of such a significant decision as MAiD. These concerns motivate the argument that legal safeguarding cannot protect mature minors from harm due to their specific vulnerabilities, and that a prohibition is justified based on the duty to protect mature minor interests that outweighs the duty to their autonomy.

2.2 Introduction

This chapter will examine the conceptual value conflict underlying the issue of MAiD for mature minors, with a particular focus on the potentially competing values of autonomy and welfare in the child and adolescent context. The chapter starts with an exploration of personal autonomy. This includes the development of capacity to make healthcare decisions, a central component of autonomy that lies at the heart of the Carter decision. Autonomy also includes the ability to make goals, commitments, and possess a strength of will; abilities that, in the healthcare context, can be enhanced by prior personal experience of illness. Drawing on both philosophy and the literature in developmental psychology, this chapter will explore the debate over whether these considerations mean that some minors, mainly older adolescents, have sufficient capability, ability, and experience to consent to MAiD.

The chapter then turns to an exploration of child welfare, analyzed in terms of child vulnerability to abuse and error. There is some recognition that vulnerability varies from individual to individual based on a diversity of interests, and the way that such interests can be violated. Yet, as developing beings and as dependents, there is a recognition that children's interests are flexible and transient, and may be less informed than those of adults – rendering them more vulnerable as a cohort. This increased vulnerability informs adult duties of beneficence to protect children's well-being. Some experts also make reference to adult duties corresponding to a child's right to an open future – restricting present choices to enable future choices as an autonomous adult.

2.3 Personal Autonomy

The concept of personal autonomy ascribes a certain moral status to human beings equally, on the basis that they are self-governing creatures (Archard, 2009, p 4). This status, which is often restricted to adults, grounds our moral and legal respect for individuals' decision-making authority – the idea that they should be “permitted, subject to certain qualifications, to make their own decisions about matters affecting only their own interests” (Archard, 2009, p 4). This permission to make decisions on matters affecting their interests is expressed in terms of the value of self-determination, which involves either having the opportunity to set or actually setting goals for oneself (Bou-Habib and Olsaretti, 2015, p 28). Self-determination differs from independence, which assigns value in not having goals set by others (Bou-Habib and Olsaretti, 2015, p 28).¹³

The authority to make decisions for oneself as well as the liability for the consequences of those decisions is often conceived as a straightforward function of one's agency and ability (McLeod, 2015, p 54). It is acknowledged that adults differ from one another in their ability to make independent, sensible, and prudent choices (Archard, 2009, p 4). Yet in spite of these differences, insofar as adults are recognized as having a basic capacity to choose how to lead their own lives, the principle of autonomy asserts that they should be allowed the freedom to exercise that capacity (Archard, 2009, p 4). Adults, typically characterized as mature and having both full authority and liability, are differentiated from children, who are typically characterized as immature, and lacking full authority and ability (MacLeod, 2015, p 54).

The capacity of children to make decisions is a significant factor in their authority to self-determine in their medical decision-making, and their right to confidentiality (Cherry, 2013, p 317). Determinations of capacity for adults and adolescents focus on similar considerations, including understanding relevant information and facts, demonstrating appreciation of the decision and its consequences of the decision, manipulating information in a rational way, reasoning, relating between ideas, and making inductive and deductive inferences (Diekema, 2011, pp 210–211; Bou-Habib and Olsaretti, 2015, p 27). Adolescents with sufficient capacity to make a decision must be able to demonstrate not simply the ability to understand and reason, but also a high level of psychosocial maturity (Diekema, 2011, p 211). This includes an ability to project meaningfully into the future,

¹³ In principle it is possible for people to independent while failing to be self determined (a fickle person in the grip of her changing whims is an example) (Bou Habib and Olsaretti, 2015, p 23). The authors also distinguish achieving independence through being self-determined from being truly independent (Bou Habib and Olsaretti, 2015, p 23).

express relatively settled beliefs and values, and being driven by long-term interests rather than short-term concerns in their decision (Diekema, 2011, p 211). Meanwhile children who do not have sufficient capacity to make health care decisions, have preferences, propensities, and inclinations that are not always authoritative (Bou-Habib and Olsaretti, 2015, p 28).

2.4 Autonomy and Child Development

The following section describes a variety of relevant factors in regarding the autonomy of children.

2.4.1 Development of Capacity

A generalized sense of children's capacity is understood according to child development studies. Children develop the capacity to exercise their autonomy gradually and to increasing degrees (Bou-Habib and Olsaretti, 2015, p 27). Minors' capacity is commonly described in terms of the "rule of sevens," which distinguishes between periods of child development among infants/young children (under 7), children (between 7 and 14), and adolescents (over 14) (Steinberg, 2013, p 265). From infancy to early childhood the frontal lobes of the brain develops rapidly, resulting in abilities to plan and organize activities, focus on tasks, become more self-sufficient, care for oneself, follow instructions, and identify letters (Cohen-Almagor, 2018, p 235). Some degree of logical reasoning develops by mid-childhood, but children lack abstract perception – their reasoning must be applied to specific examples (Cohen-Almagor, 2018, p 235). Between the ages of 10 and 12, the frontal lobes of the brain mature further, enabling the capacity to construe, make logical assumptions, and plan (Cohen-Almagor, 2018, 237). Abstract thinking is obtained between late childhood and mid-adolescence (12–16), Minors are then able to reason, develop systematic thinking, extrapolate information, and use logic. Regions enabling primary functions, such as the motor and sensory systems, mature earliest. Higher-order association areas, which integrate these primary functions, mature later. (Cohen-Almagor, 2018, p 237).

Based on several empirical studies, some authors conclude that by the age of 14, the ability of adolescents to make rational and reasonable health care decisions approximates that of adults (Buchanan and Brock, 243; Jackson and McRae, 2013, web). For instance, Douglas Diekema refers to a study by Weithorn and Campbell (1982), which revealed no significant difference between 14-year-olds and adults in the ability to express reasonable preferences regarding medical treatment based on evidence, reasonable outcome, understanding, and rational reasoning (2011, p 211). Some authors mark the lower threshold of autonomy at 12–14, since minors in early adolescence and of younger age find it hard to make predictions about things of which they have no experience (Cohen-Almagor, 2018, p 235). In particular, some experts have concerns that children younger than 12–14 lack sufficient autonomy to decide monumental end-of-life decisions. (Cohen-Almagor, 2018, p 235).

2.4.2 Goals, Commitments, Strength of Will

While the development of children's cognition shapes our understanding of their autonomy according to their decision-making capacity, some authors argue that children have additional abilities which demonstrate agency. These include the ability to appreciate value, to hold goals and commitments, and to have a sufficient strength of will to act in line with their values and wishes (Bou-Habib and Olsaretti, 2015, pp 27–28). Incapable children, who may be unable understand and form reasonable preferences regarding medical treatment based in evidence and outcomes, have some ability to act in line with their commitments, and therefore possess some degree of agency, even in early childhood (Bou-Habib and Olsaretti, 2015, p 27). Whether or not children have consciously reflected upon their commitments and goals, there are items, activities, people, experiences, and relationships that they prioritize and value and which inform their goals. For example, “continu[ing] relationships with friends and loved ones, keeping prized possessions, engaging in favourite activities, feeling pleasure, pleasurable excitement, and feeling comfortable and at ease, mastering new and challenging tasks, being recognized for skills and accomplishments, and avoiding significant stress and pain” (Mullin, 2013, p 416).

Meanwhile, some children demonstrate strength of will to act in line with their wishes. This refers to the ability to independently form conclusions and motivate action on the basis of that which they prioritize and value (Bou-Habib and Olsaretti, 2015, p 28; Mullin, 2013, p 416). An example where a ‘strength of will’ is absent is a case where a child understands that brushing their teeth regularly would avoid painful dental treatment in the future, yet still stubbornly refuses to brush her teeth (Bou-Habib and Olsaretti, 2015, p 28). Strength of will is related to self-control: the ability to avoid external distractions or internal shifting thoughts and feelings (Mullin, 2013, p 416). Activities which are not intrinsically rewarding require significantly more self-control to forgo fleeting pleasures, work hard, and risk failure (Mullin, 2013, p 416). In asserting that children are capable of significant self-control in service of their goals, Mullin raises the example of perseverance in sports which requires practice, pain, and periods of disappointment (Mullin, 2013, p 416). These expressions of agency alone do not indicate that a child has decision-making authority, yet they suggest that children may still play a role in shaping decisions about matters affecting their interests. Indeed, in a position statement, the Canadian Paediatric Society (CPS) recommends that where children and adolescents are not capable and cannot consent, their assent and dissent must be respected wherever possible (Coughlin, 2018, web). Further, they claim that children and adolescent's participation in medical

decision-making should always be sought, with proportionate involvement according to their capacity and circumstances (Coughlin, 2018, web).

2.4.3 Personal Experience of Illness

Decision-making capacity may also be demonstrated by experience. Pricilla Alderson argues that children's competence and autonomy develop through direct social personal experience (Alderson, 2007, p 7). Childhood research reveals higher competencies in young children and that adversity may increase knowledge, skills, and courage. This has been demonstrated through interviews with children who have prior lived experience with illness and treatment (Alderson, 2007, p 7; Diekema, 2011, p 211). Children as young as two years have demonstrated knowledge of the names and purposes of their cancer drugs, and have deliberately withheld the degree of their knowledge and suffering from their parents for their protection (Alderson, 2007, p 7).

This lived experience is especially impactful among children who have long-term conditions (Alderson, 2007, p 8). Children with long-term conditions demonstrate an informed commitment to strict diet, daily injections, medicines, or physiotherapy which exceeds passive compliance – for instance, children with diabetes refusing sweets which their friends enjoy (Alderson, 2007, p 8). By the age of four or five, children map their life-long understandings of self, others, and relationships; time and space, art, and much basic science (Alderson, 2007, p 8). By this reasoning, adolescents considering treatment which they have previously received, or who are making a decision about an illness they have experienced long-term are more capable to make autonomous decisions and should be granted more decision-making authority. These findings support the conclusion that minors have medical decision-making capacity and should not be denied the right to self-determination (Diekema, 2011, p 216). Noting that the degree of care, information, support, respect, and involvement in the decision can affect a child's capability and may give rise to fearful misunderstandings, Pricilla Alderson recommends informing children as much as possible about the nature, purpose, and likely effects of interventions (Alderson, 2007, p 8).

2.4.4 Adolescents: Sufficiently Capable?

Thus, considerations of child development according to age and physical growth seem to indicate that children over 14 are sufficiently mature to make their own medical decisions. Factoring in a child's prior experience could mean that they reach a sufficient level of maturity at a younger age. Yet there is apprehension that, even where children have the capacity to make decisions, they are not

miniature adults (Hester, 2012, p 115). In the context of research, Micah Hester gives the example of the belief that dosage used on adults can simply be reduced for children, which has led to a lack of paediatric-tested medicines (2012, p 115). Likewise, while a 12-year-old child's brain has the size, folding, weight, and regional specialization of an adult's, it still has a long way to go to reach adulthood (Cohen-Almagor, 2018, p 237). The differences in brain development between adults and adolescents could make the prospect of "empowering [mature minors] with the capacity to end their lives a dangerous proposition. (Cohen-Almagor, 2018, 236).

During adolescence, there are substantial changes in the density and dopamine receptors of pathways connecting the limbic system, where emotions are processed and rewards and punishments are experienced (Cohen Almagor, 2018, p 237). Some authors argue that an adolescent brain's prefrontal cortex and executive functions are still slowly developing, affecting their inhibition, mental flexibility, ability to plan, reasoning, problem-solving, working memory, action initiation and monitoring, experience of reward and punishment, emotional response, self-regulation of behaviour, and decision-making (Cherry, 2013, p 319; Chan et al., 2008).

Others accept the premise that mature minors have intellectual and rational capacity, but distinguish between adults' and adolescents' psychosocial competence (Diekema, 2011, p 222). Douglas Diekema argues that this difference in capacity results from adolescents having a relatively underdeveloped prefrontal cortex, affecting functions essential to good decision-making (2011, p 222). These include "high level reasoning, impulse control, assessment of future consequences, planning, strategizing, organizing, inhibition of inappropriate behavior, adjustment of behavior when a situation changes, priority setting, and estimating and understanding probabilities" (Diekema, 2011, p 222).

These differences in cognitive function undermines minors' capacity to make medical decisions (Diekema, 2011, p 222). For instance, adolescents are more affected by the emotional context and the influence of their peers, are less future-oriented, are more impulsive, and differ from adults in their risk-benefit assessments (Cherry, 2013, p 319; Diekema, 2011, p 222). While minors are capable of achieving a certain number of practical goals, until a rather late stage they still do not know how exactly these goals are accomplished and have an immature perception of how risks apply to them (Cohen-Almagor, 2018, p 235; Cherry, 2013, p 319). Further, adolescents are prone to act on emotions rather than reason, and have a tendency to sensation-seeking that is not always rational and calculated (Cohen-Almagor, 2018, p 236). The ability to think about the future, plan ahead, and

anticipate future consequences, and to act less impulsively increases gradually through adolescence (Diekema, 2011, p 222), but does not peak until well into one's twenties (Cohen-Almagor, 2018, p 237; Diekema, 2011, p 222).

The cognitive differences between adults and adolescents (which may impact adolescent executive functions, psychological competence, and their reactive socioemotional systems) are evidenced by novelty-seeking behaviours and poor choices (Cherry, 2013, p 320). These choices include experimentation with risky sexual practices, drugs, alcohol, and gambling, with an increased risk of addiction (Cohen-Almagor, 2018, p 237; Cherry, 2013, p 319). Authors also point to increased incidence among adolescents of fast driving, injury, unintended pregnancy, sexually transmitted infections, committing and being the victim of violence, homicide, and suicide as evidence of diminished capacity to make decisions (Cohen-Almagor, 2018, p 237; Cherry, 2013, p 319).

Thus, despite being considered capable of making medical decisions, mature minors may not make decisions which reflect the cognitive capacity characteristic of adults (Diekema, 2011, p 222). This could be attributed to insufficient brain maturation to justify being treated as adults in making health care decisions with a significant risk of harm (Diekema, 2011, p 223). Alternatively, adolescents may possess sufficient brain maturation, but do not use their abilities optimally due to psychosocial and socioemotional factors (Diekema, 2011, p 222). These considerations particularly undermine rational and intellectual decisions in conditions of high stress or emotion, peer presence or pressure, and perceived short-term benefit (Diekema, 2011, p 211). Though adolescents may "know better" and can balance the harms and benefits of their decisions, they are routinely driven to make more risky decisions (Cherry, 2013, p 320). These considerations are made more complex by the social and emotional context of real-life decision-making in a medical crisis (Diekema, 2011, p 222). A related concern is that children and adolescents may be vulnerable due to being sensitive to pressure from others and social expectations. As a result, they "are more prone to act on social expectations than on what they truly want" (Bovens, 2015, p 631). Consciously or subconsciously, it is possible that children and adolescents may identify their personal preference but opt against it for the sake of their parents, caregivers, and the medical team (Bovens, 2015, p 631).

Based on these concerns that children do not have inhibition, emotional and behavioural self-regulation, and psychosocial competence, they may not be sufficiently mature to consent to MAiD. If autonomy involves an abilities to self-regulate emotions, engage in long-range planning, weigh present and future rewards, and properly assess risks, then adolescents lack an important degree of

autonomy. These concerns are likewise used to justify restricting children from making other kinds of decisions, regardless of their decision-making capacity. These include restricting voting and performing other duties of citizenship; joining military service; having sexual intercourse, getting married, and raising children; drinking alcohol and smoking tobacco; and dropping out of school (Cohen-Almagor, 2018, p 238; Kaczor, 2016, p 57). Minors are also held less accountable for their decisions in the criminal justice system, and receive different sentencing than adults (Cohen-Almagor, 2018, p 238; Kaczor, 2016, p 57). Opponents of mature minor access to MAiD argue that these age distinctions acknowledge that challenging decisions require a certain degree of mental and physical faculty, maturity, and responsibility that is developed at a later stage of life (Cohen-Almagor, 2018, p 238). This argument, referred to as the argument from consistency, will be discussed in more detail in Chapter 6.

2.5 Vulnerability

These potential limitations to adolescent mature decision-making raise questions about whether restricting a child's choices is justifiable. The central consideration in restricting a child's decisions is the impact of a child's decision on their well-being (Bou-Habib and Olsaretti, 2015, p 18). Some accounts of autonomy hold that "respecting a person's autonomy matters for its own sake, independently of, and perhaps in spite of, the impact of doing so on her well-being" (Bou-Habib and Olsaretti, 2015, p 18). Yet other accounts hold choosing, or at least endorsing, goods which positively contribute to/avoid diminishing one's well-being as an end of autonomy (Bou-Habib and Olsaretti, 2015, p 18). Where well-being is prioritized in conceptualizing children's autonomy, children's vulnerability becomes a primary consideration. The relationship between values of autonomy and well-being in the common law will be discussed further in Chapter 4.

Whether conceptualized independently or as part of autonomy, the notion of constraining the actions of children in the interest of their well-being may be compatible with promoting their autonomy by preventing decisions which are not an exercise of one's capacity (Bou-Habib and Olsaretti, 2015, p 28). Bou-Habib and Olsaretti argue that overriding children's decisions is most straightforward where children lack the reasoning ability required to make a choice (2015, p 28). Where children lack sufficient reasoning skills to make a particular decision, self-determination does not exercise one's capacity, and therefore does not serve one's autonomy (Bou-Habib and Olsaretti, 2015, p 28). Bou-Habib and Olsaretti give the example of providing medical treatment (including visits to the doctor and administration of foul-tasting medicine) against an incapable child's wishes as an illustration of restricting choice in ways that are not autonomy-limiting. Thus, while adults are permitted to make harmful decisions based on the presumption that they are acting autonomously, children's wishes can be overridden in favour of their welfare where their wishes are clearly not autonomous.

Vulnerability is related to the concept of well-being. It involves susceptibility to harm (Macleod, 2015, p 55), and is an important factor in describing the special moral status of children, and identifying risks and benefits in determining their well-being (Schweiger and Graf, 2017, p 244). Children are frequently characterized as a class of vulnerable persons who are physically, economically, and emotionally vulnerable due to their lack of knowledge and capabilities, flexibility, and the sensitivity of child development (which may become distorted with potentially severe effects) (Schweiger and Graf, 2017, p 246; Benporath, 2003, p 138). While there is potential that these

characteristics of childhood will enable discovery, experimentation, and the open-minded development of their identities as they grow, there is also a risk that children may be harmed by experiencing disempowerment, endangerment to their lives and well-being, and exploitation (Benporath, 2003, p 137). Benporath warns that, by evading the centrality of children's vulnerability, we may fail to "protect children's lives and well-being, and ... deprive... them of their ability to thrive" (2003, p 143).

The nature of vulnerability varies considerably between persons, and is dependent on two considerations. One is the person's substantive (i.e., the content of their) interests: people have different interests, and thus vary in how they can be injured (MacLeod, 2015, p 55). Generally, children have interests in stable family relationships, early bonding, freedom from pain and suffering, and keeping the future open (Friedman Ross, 2009, p 311). Further, in addition to more generic interests, children have particular interests which include specific fears, sources of suffering, future goals, and the specific culture, religion, and values of the family (Friedman Ross, 2009, p 311). Thus children's substantive interests are multifaceted, depending on both "the way children are and on the context in which they live" (Schweiger and Graf, 2017, p 244).

There is a common assumption that vulnerability reduces as children develop mature agency (MacLeod, 2015, p 54). Yet as developing beings, children's vulnerability is dynamic rather than static, and varies according to their age. The vulnerability of newborns is very different from that of teenagers, whose interests and risks vary enormously (Schweiger and Graf, 2017, p 245). The transience of children's interests and risks may cause them to be a more vulnerable class of person than adults. Some authors believe that adults have more capacity to appreciate value, and more settled preferences and dispositions than children, determining their interests with more accuracy (Bou-Habib and Olsaretti, 2015, p 29). Thus an adult's initial judgments of what would be beneficial to them is more reliable than the initial judgments of a child (Bou-Habib and Olsaretti, 2015, p 29).

Restricting mature minors from access to MAiD is defended on grounds of protecting children as vulnerable persons. Children are a distinctly vulnerable cohort due to concerns that they lack ability to make autonomous decisions.¹⁴ Children's lack of knowledge and capabilities, their flexibility, and the sensitivity of child development can put children at greater risk of harm through disempowerment,

¹⁴ Although vulnerability is often conceptualized such that it diminishes autonomy, some authors argue that there are some cases where this is not true. Joel Anderson argues that autonomy requires some forms of vulnerability, which plays a vital role in personal relationships (2014, p 139).

endangerment to their lives and well-being, and exploitation. This vulnerability is made more complex by children's development, which results in dynamic interests and risks of harm, and raises uncertainties about whether a child can appreciate value, determine their own interests, or hold stable and settled preferences. If these challenges do not justify an absolute prohibition on mature minor access to MAiD, they may at least support increased safeguarding, which may impose greater restrictions on mature minors than on adults.

2.5.1 Duty of Beneficence to Children

Children's distinct vulnerabilities may warrant obligations to protect their substantive interests from threats, which also vary from person to person (MacLeod, 2015, p 55). Children are innately dependent on others to secure their basic interests (Schweiger and Graf, 2017, p 246). Recognition and respect for children's dependency and corresponding vulnerabilities based on this dependency justifies a corresponding duty of beneficence on the part of adults (Benporath, 2003, p 138). Yet a common view in the literature regarding duty of beneficence to children is that this does not justify a *carte blanche* to make paternalist decisions on behalf of children (Benporath, 2003, pp 136, 138). Specifically, there is a risk that a child's decisions are restricted based on mere disagreement with their choice (Hester, 2012, p 120). Rather, children's vulnerability justifies a weak form of paternalism to benevolently protect them from violations of their interests and well-being, and to give attention, care, and support to their well-being to enable their growth and development (Benporath, 2003, pp 136, 138). Adults therefore have obligations to monitor their lives closely, regulate their behaviour, assist them in learning norms and conventions, and provide them with goods they cannot procure for themselves (Benporath, 2003, p 138).

The dependency of children's well-being upon the way they are perceived or treated by adults highlights the relational aspect of vulnerability (Benporath, 2003, p 137). Vulnerability to others is not only based on the risk that they may cause one harm, but also in one's dependency on others for care – “always to some extent, and more dramatically when young, ill or disabled” (Mullin, 2014, p 267).¹⁵ We are vulnerable to the action or inaction of others when we need their help (Mullin, 2014, p 267). Likewise, when our needs cannot be met without care provided by others, we are dependent on others and vulnerable to their willingness to provide us the care we need (Mullin, 2014, p 267). Some

¹⁵ Thus, when it comes to MAiD, vulnerability is more acute in the mature minor context than the adult context, based on an intersection of dependency based on age together with other factors which increase one's dependency (e.g., illness or disability).

characterize the nature of adults' relationships with children in terms of protective paternalism, to supporting children's well-being without inhibiting their future development, including future ability to choose and thrive (Benporath, 2003, pp 136, 138).

Likewise, health care providers have an ethical duty to the well-being of children (Diekema, 2011, p 223). Diekema argues that health care providers have a duty of beneficence to seek the good of the paediatric patients and to minimize harms (2011, p 223). To treat children with beneficence recognizes that respect and encouragement to be involved in decision-making improves well-being, but also requires protecting children by preventing harms that might result from an unsupervised decision (Diekema, 2011, p 223). In protecting children's well-being, health care providers consider factors such as the "likelihood of a good outcome, the burden of proposed interventions, and the duration and frequency of the proposed interventions" (Hester, 2012, p 120). In particular, a high efficacy of the treatment may raise questions about whether failing to provide treatment constitutes medical neglect (Hester, 2012, p 120). Alternatively, "high stakes" consequences of failing to provide treatment may warrant that children be protected from significant harm (Hester, 2012, p 120).

Based on these considerations of child vulnerability, some argue that the extent to which children and adolescents should be able to make decisions depends on the degree of risk inherent in the decision. Where children and adolescents should be permitted to make low-risk decisions, which pose limited risk of harm, some argue that children and adolescents should be protected from making high-risk decisions that may pose the risk of significant harm to children's well-being. This will be discussed in more detail in Chapter 5, which gives a more in-depth discussion of risk and well-being.

2.5.2 Duty to a Child's Open Future

In addition to being motivated by a duty of beneficence, overriding children's exercise of their wishes may be motivated by a duty to a child's open future, or their "long-term autonomy" (Friedman Ross, 2009, p 311). The view that children have a right to an open future conceptualizes autonomy as an "end state" achievement of a self-determined life where one rationally deliberates and pursues one's goals (Bou-Habib and Olsaretti, 2015, p 19). Children's future achievement of rational self-determination constrains child-rearing so that it does not undermine the child-as-adult's capacity for autonomy (Bou-Habib and Olsaretti, 2015, p 19). These constraints may include overriding their current autonomy in order to promote their "lifetime autonomy and opportunities" (Friedman Ross, 2009, p 311). Children's lack of worldly experience, decision-making capacity, and ability may justify such restrictions to provide them with guidance and opportunity to develop their capacity and

“enabling virtues” of autonomy, such as the habit of self-control (Friedman Ross, 2009, p 311). Upon reaching adulthood, the advantages of self-determination outweigh the benefits of developing lifetime autonomy (Friedman Ross, 2009, p 311).

The idea that we may have an obligation to overrule the wishes of children, but not adults, in order to preserve their long-term autonomy can be in defence of prohibiting children from accessing MAiD. This argument is based on the premise that MAiD carries a higher level of risk due to the finality of the decision, which cannot be reversed or mitigated, and so requires a much higher level of scrutiny compared to other medical decisions (Kaczor, 2016, p 57). From this reasoning, some assert that minors should be held to a different standard in the case of life-and-death decisions. This argument will be examined in closer detail in Chapter 6, which discusses whether a prohibition on mature minor access to MAiD is justified because MAiD carries a special moral status.

2.5.3 Parental Interests and Authority

In addition to considerations of duties to the child (beneficence, right to an open future), there is some question on whether there are duties to the parents, or parental rights. In discussing limitations of child decision-making authority, Friedman-Ross makes reference to a “parental interest in raising their child according to their own vision of the good life” (2009, p 311). Based on this view, one can argue that, even where adolescents become sufficiently capable, parental authority overrides claims to an adolescent’s sole decision-making authority in cases of life-and-death decisions until the age of emancipation (Friedman Ross, 2009, p 311). These questions about parental rights are present in discourse in Belgium and the Netherlands, the two jurisdictions where minors are permitted access to euthanasia.¹⁶

While this work acknowledges that parental authority is part of the literature on minors and end of life, especially in jurisdictions outside Canada, the issue of parental authority will not be addressed in this dissertation. In part, the concept of parental authority conflicts with the central ethical justification underlying MAiD – the exercise of personal autonomy and dignity. Under this lens, it is

¹⁶ In Belgium, legal representatives (who are almost always the parents) must give consent, which should be formally documented (Raus, 2016, p 311). In the Netherlands, from ages 12 to 16 minors requesting euthanasia require consent of the parents or guardian (Government of the Netherlands, NDA, web). From 16 to 17, parental consent is not required, but parents must be involved in the decision-making process (Government of the Netherlands, NDA, web). Euthanasia is also legal for infants up to one year old with parental consent. Recently, the Dutch government has approved plans to allow euthanasia for terminally ill children aged between 1 and 12, expected to be implemented within the next few months (BBC, 2020, web). Requests for euthanasia from children under age 12 would likewise require parental consent (BBC, 2020, web).

unclear how the personal interests of others could be authoritative in the exercise of one's capacity to make an autonomous decision. This conflict is raised in the Belgian context, where parental consent is argued to be inconsistent with claims that some minors are competent to request euthanasia (Raus, 2016, p 311). Moreover, the concept of parental authority over a capable child is incompatible with the statutory and common law structures which underlie child and adolescent health care decision-making. This will be discussed further in Chapter 3.

2.6 Conclusion

This chapter gave analysis of values of autonomy and welfare (in terms of vulnerability) in the context of MAiD, focusing specifically on significant considerations in the child and adolescent population. Autonomy is the fundamental moral value of self-governance, such that autonomous persons are treated with authority to make decisions affecting their own interests and set personal goals. The ability to exercise autonomy is developmental, such that infants are presumed not to be autonomous, while adults are presumed to be autonomous. Autonomy involves a range of abilities. Cognitive or intellectual abilities are necessary to understand medical decisions, and express rational and reasonable preferences. There is a general indication in child development literature that adolescents over 14 have sufficient cognitive and intellectual ability to consent to medical treatment. Yet the literature also suggests that social and emotional abilities are significant to exercising autonomy. Even where intellectually capable adolescents may not possess sufficient emotional and behavioural inhibition, self-regulation, and psychosocial competence to exercise autonomy. This could affect their ability to anticipate the future, plan ahead, and act less impulsively. This reveals some uncertainty about whether mature minors possess sufficient abilities to act autonomously, and raises the question of which abilities should be prioritized when it comes to autonomous decision-making. Balancing mature minor cognitive-intellectual and social-emotional abilities to exercise autonomy relates to children's vulnerability, along with adults' duties of beneficence and to a child's right to an open future. These questions will be discussed further in Chapters 5 and 6 of this work.

This chapter also reveals that autonomy develops in degrees in a way that is specific to the individual and the context. Even among adults, there is variation in abilities to make independent choices. Yet adults are presumed autonomous in spite of these differences by having reached a basic threshold of capacity to self-determine. Given the variance in mature minor abilities to make an autonomous decision, along with their particular vulnerabilities, another question is: What is the threshold of mature minor capacity required to be considered autonomous under the Canadian legal and policy framework? Much like cases of adolescent refusal of life-sustaining treatment, the balance of these values is challenging, requiring "reflection, discussion, and principled determinations" (Hester, 2012, p 120). This will be considered further in Chapter 3, which reviews the legal landscape of mature minor consent to treatment. Acknowledging concerns that requesting and consenting to MAiD is an especially risky and difficult decision to make; a related question is what the right

threshold of ability and capacity ought to be for mature minors to be considered sufficiently autonomous to consent to MAiD.

Chapter 3

The Legal Landscape Informing Mature Minor Consent in Health Care

3.1 Introduction

The previous chapter analyzed mature minor eligibility for MAiD in terms of an underlying conflict of values between welfare and self-determination. While the tension between these values is common to issues in clinical ethics more generally, such as situations where patients choose to live at risk or consent to treatment that poses a significant risk of harm, the tension is particularly acute in cases involving mature minors. After all, childhood development studies reveal uncertainty regarding adolescent maturity and ability to make autonomous decisions, which obscures our ethical obligations to mature youth. These uncertainties concern whether mature minors can meet the threshold of ability to be considered autonomous, and whether the particular risks which mature minors face, along with welfare duties to children, ground a higher threshold of capacity.

Ethical obligations to mature minors are set out in provincial and federal legal mechanisms which govern health care decision-making. Legislation and landmark court cases which guide legal judgments mould the challenges in health care decision-making, and can give guidance in resolving ethical challenges. Meanwhile, balancing the ethical values of welfare and self-determination can help interpret how we ought to balance legal obligations to mature minors. This chapter considers these obligations by providing background on some of the legal mechanisms which underlie mature minor consent to MAiD. This background includes legislation and common-law precedent which guide health care decision-making more generally, in addition to some particular legal considerations in cases of a health care decision made by a mature minor. In examining both legislation and common law, I find that the ethical conflict of value underlying the treatment of mature minors is reflected in the law – where the law sometimes defers to mature minor self-determination, and at other times restricts mature minor decision-making in the interest of protecting their welfare.

3.2 Applicability of International Children’s Rights

The Universal Declaration on Human Rights (UDHR), originally formulated as ‘soft law’ (aspirational and not legally binding), was adopted as part of customary international law through the ratification of two legally binding covenants in 1976: the International Covenant on Civil and Political Rights (ratified by 168 nations); and the International Covenant on Economic, Social and Cultural Rights, (ratified by 164 nations) (United Nations Humans Rights Office of the High Commissioner, 1996–2021, web). Despite the legally binding nature of the UDHR and the development of additional conventions on particular human rights concerns, such as the Convention on the Rights of the Child (CRC), in practice most legal work to secure or enforce human rights is conducted at the national and regional level (United Nations Humans Rights Office of the High Commissioner, 1996–2021, web). Meanwhile, international declarations such as the CRC are mostly used as a model for structuring local constitutional and legislative arrangements (United Nations Humans Rights Office of the High Commissioner, 1996–2021, web).

Thus, our legal obligations to children are shaped by international legal instruments. Canada is a signatory to the CRC, which guides our common-law obligations to mature minor consent to treatment through articles 3, 5, 12, and 14. Article 3(1) articulates duties to act in the best interests of the child:

In all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration. (United Nations Humans Rights Office of the High Commissioner, 1996–2021, web)

Article 5 details parental rights:

States Parties shall respect the responsibilities, rights and duties of parents or, where applicable, the members of the extended family or community as provided for by local custom, legal guardians or other persons legally responsible for the child, to provide, in a manner consistent with the evolving capacities of the child, appropriate direction and guidance in the exercise by the child of the rights recognized in the present Convention. (United Nations Humans Rights Office of the High Commissioner, 1996–2021, web)

Article 12(1) balances child rights to self-determination with other CRC rights:

States Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters

affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child. (United Nations Humans Rights Office of the High Commissioner, 1996–2021, web)

Article 14 articulates child rights to freedom of religion, as well as limitations on those rights:

1. States Parties shall respect the right of the child to freedom of thought, conscience and religion.
2. States Parties shall respect the rights and duties of the parents and, when applicable, legal guardians, to provide direction to the child in the exercise of his or her right in a manner consistent with the evolving capacities of the child.
3. Freedom to manifest one's religion or beliefs may be subject only to such limitations as are prescribed by law and are necessary to protect public safety, order, health or morals, or the fundamental rights and freedoms of others. (United Nations Humans Rights Office of the High Commissioner, 1996–2021, web)

Article 30 articulates Indigenous and ethnic, religious, and linguistic minority rights to language, culture, and religion:

In those States in which ethnic, religious or linguistic minorities or persons of indigenous origin exist, a child belonging to such a minority or who is indigenous shall not be denied the right, in community with other members of his or her group, to enjoy his or her own culture, to profess and practise his or her own religion, or to use his or her own language. (United Nations Humans Rights Office of the High Commissioner, 1996–2021, web)

These passages highlight obligation of both acting in the best interest of the child, and of respecting the child's own wishes and decisions. These two values may come into conflict in challenging situations where children's well-being seems to conflict with the expressed wishes of the child, which will be discussed later in this chapter. The CRC is enacted in Canadian law principally through the courts,¹⁷ which use the Charter as a tool to interpret children's rights and the application of the CRC. In particular, the CRC serves as context in weighing any proposed justification for children's Charter rights under s. 1, as it provides a standard to examine and compare what is acceptable in Canada and other democratic societies. There is no Charter right or freedom which explicitly states the rights of a child. Yet there are core CRC rights found within the Charter. For instance, Article 2 protects children

¹⁷ There are some cases where the CRC is referenced in legislation (e.g., the Supreme Court acknowledged the CRC is referenced in the preamble of the Youth Criminal Justice Act).

from discrimination, and is similar to s. 15 of the Charter. Other CRC rights are outlined within Charter provisions (Canadian Bar Association, 2021, web). An example is the Article 12 CRC right to consideration of the child's views and wishes, which is part of due process within the principles of fundamental justice under s. 7 of the Charter (Canadian Bar Association, 2021, web). In addition, certain statutory law reflects the CRC – for instance, the Child, Youth and Family Services Act (2017), which will be discussed in the following section of this Chapter.

3.3 Age and Statutory Health Care Consent across Canada

In Canada, health care falls under provincial jurisdiction and so is mainly regulated by provincial legislation, although some aspects of health care are regulated federally.¹⁸ In addition there are some cases where healthcare is governed by both provincial and federal legislation. MAiD is an example, as it is subject to provincial civil law governing consent to treatment, but is also governed by Bill C-14 and recently Bill C-7, which amends the Criminal Code of Canada. Another example is the detention of a person with a mental disorder (Byrick and Walker-Renshaw, 2016, 1-1). In such cases, the criteria under the civil law of the province regulating involuntary admission can differ from those in the federal law governing the detention and release into the community of a mentally disordered criminal offender (Byrick and Walker-Renshaw, 2016, 1-1). While analysis in this dissertation will focus on provincial statutory law governing consent to health care in Ontario, legislation varies from province to province with respect to minors and health care decisions (especially Quebec, which uses a system of civil law).

Most Canadian provinces specify no age of consent with respect to treatment. Quebec and New Brunswick specify an age of consent to medical treatment. The Quebec Civil Code states that a 14-year-old can consent to care with the exception of circumstances where the care is not medically required and entails a health risk, which necessitate the consent of a parental authority (Jackman and McRae, 2009, web). Quebec's Act Respecting End of Life Care defers to the Civil Code by stating that to the extent provided by the Civil Code, a minor of 14 years of age or older may refuse or withdraw consent to receive life-sustaining care (2014, c. 2, s. 5.; Council of Canadian Academies, 2018, p 52). New Brunswick's Medical Consent for Minors Act explicitly states that "the law respecting consent to medical treatment of persons who have attained the age of majority applies, in all respects, to minors who have attained the age of sixteen years in the same manner as if they had attained the age of majority" (SNB 1976, c. M-6.1). Under the common law, adult consent operates based on a presumption of capacity (i.e., the presumption that they are capable unless this can be rebutted by evidence of incapability). Meanwhile, consent for minors operates on the presumption of incapacity (i.e., they are presumed incapable unless this presumption is rebutted by evidence that they

¹⁸ The federal government regulates Canada's publicly funded health care insurance as well as financial support to the provinces and territories under the Canada Health Act (Byrick and Walker-Renshaw, 2016, 3-1). The federal government also provides certain direct health care services to some population groups, including First Nations people living on reserves, Inuit, serving members of the Canadian Forces, eligible veterans, inmates in federal penitentiaries, and some groups of refugee claimants (Government of Canada, 2016, web).

are capable). The Medical Consent of Minors Act codifies that minors 16 years or older are presumed capable as though they were adults; however, this does not entail that a minor over 16 cannot be found incapable with respect to treatment (Council of Canadian Academies, 2018, p 57). The concept of presumption of capacity will be discussed further in section 3.

The remaining provinces and territories do not specify an age of consent to medical treatment, though each does allow that those under the age of 18 can consent to treatment in some cases. British Columbia specifies no minimum age: section 17 of the Infants Act states that “a person under 19 may consent to treatment if the healthcare provider is satisfied that the minor demonstrates capacity and deems the treatment in the minor’s best interest” (Council of Canadian Academies, 2018, p 53). Section 4 of Ontario’s Health Care Consent Act outlines the conditions under which a person is deemed capable to make health care decisions, again specifying no minimum age (Council of Canadian Academies, 2018, p 55).

Prince Edward Island’s Consent to Treatment and Health Care Directives Act contains a rebuttable presumption of capability to consent to or refuse medical treatment that is not age specific. Yukon’s Care Consent Act outlines that rather than an age requirement, consent or refusal is dependent on whether the individual understands (i) the reason(s) why the care is proposed, (ii) the nature of the proposed care, (iii) the risks and benefits of receiving (or refusing) the care, and (iv) alternative courses of care (Council of Canadian Academies, 2018, p 58). With respect to capable decisions, Alberta, Manitoba, Saskatchewan, Nova Scotia, the Northwest Territories, and Nunavut defer to the common-law mature minor doctrine, which does not specify an age of consent (Council of Canadian Academies, 2018, pp 53–59).

While mature minors can give consent to treatment in most jurisdictions, there are legislative age distinctions when it comes to other aspects of health care decision-making, such as future decisions and decision on behalf of others. Provincial legislation also varies on the questions of age with respect to advance care planning, though most provinces and territories set the age at 16. For instance, Saskatchewan, Manitoba, and Newfoundland and Labrador have no current legislation for health care decisions by minors, but have age conditions in their advance directives statutes (Council of Canadian Academies, 2018, p 58).¹⁹ In addition to existing legislation which addresses minors’ consent to

¹⁹ Newfoundland and Labrador’s Advanced Healthcare Directives Act presumes that a person over 16 years is competent to make healthcare decisions, while a person under 16 years is not. Saskatchewan’s Health Care

healthcare, Ontario, Prince Edward Island, and the Yukon specify age conditions to exercise advance decisions.²⁰

Directives and Substitute Decisions Act, and Manitoba's Health Care Directives Act set 16 as the minimum age to make an advance directives (Council of Canadian Academies, 2018, p 58).

²⁰ Under s. 21(1)1. of the Health Care Consent Act, substitute decision makers must give or refuse consent in accordance with the person's applicable known wishes that the incapable person expressed while capable and after attaining 16 years of age (HCCA, 1996). That is, wishes expressed while the patient was capable and under the age of 16 are invalid with respect to decisions made on their behalf if they become incapable. In Prince Edward Island, the Consent to Treatment and Healthcare Directives Act, s. 3(1), does not specify a minimum age for making an advance directive. Further, s. 20(1) states that any person over the age of 16 who is capable may execute an advance directive. S. 27(1) of Yukon's Care Consent Act states that persons over 16 years are capable of making an advance directive.

3.4 Health Care Decision-Making in Ontario Legislation

3.4.1 The Health Care Consent Act (1996)

In Ontario, health care decisions are mainly governed by the Health Care Consent Act (1996). The legislation includes elements of informed consent, the test for capacity to give consent, guidance on the role of the substitute decision-maker, and the principles guiding substitute decision-makers in giving consent on behalf of another (Byrick and Walker-Renshaw, 2016, 1-6). Decisions governed by the Health Care Consent Act include consent to treatment, consent to admission to a care facility, and consent to personal assistance services (Byrick and Walker-Renshaw, 2016, 1-6).

The rights to autonomy and self-determination are upheld under the Health Care Consent Act, which states that informed consent must be given in order to receive treatment. In cases where the patient is capable, the patient must give the informed consent to treatment (1996, s. 10(1)(a)). There is no age of consent to treatment listed under the Health Care Consent Act. To meet the conditions of informed consent, a patient's consent must relate to the treatment; must be informed regarding the nature and expected benefits/risks/side effects of the treatment, alternative courses of action, and the likely consequences of not having treatment; must be given voluntarily; and must not be obtained through misrepresentation or fraud (1996, s. 11). To be capable, a patient must understand the information relevant to the health care decision, and be able to appreciate the reasonably foreseeable consequences of that decision (1996, s. 4). Patients are presumed to be capable with respect to health decisions (1996, s. 4). Capacity is also treatment and time specific: a patient can be incapable at one time or with respect to one treatment decision, but could be capable at another time or with respect to another treatment decision (1996, s. 15).

Patient autonomy extends indirectly to cases where they are incapable of giving consent. Informed consent must be given by a substitute decision-maker on the incapable person's behalf in order to receive treatment (Health Care Consent Act, 1996, s. 10(1)(b)). To fulfill their responsibility under the Health Care Consent Act, a substitute decision-maker must give consent on behalf of an incapable patient in accordance with any known prior capable wishes applicable to the circumstances (1996, s. 21(1)). When an SDM makes decisions on an incapable minor's behalf, the patient may not yet have demonstrated capacity, and hence may not have any known prior capable wishes. Where the substitute decision-maker does not know of any prior capable wishes, they must act in the incapable

person's best interests (Health Care Consent Act, 1996, s. 21(1)). The concept of best interests will be discussed in more detail in Chapter 5.

The Health Care Consent Act lists a hierarchy to determine who is the substitute decision-maker in the event that a patient is incapable, where the person who ranks highest is designated the substitute decision-maker (1996, s. 20(1)). Unless there is a court-appointed guardian of the person, a power of attorney for personal care (to be discussed in the next section), or a s. 33 representative, the parents²¹ of a child (or the Children's Aid Society (CAS) or any other person lawfully entitled to give/refuse consent in place of a parent) act as the substitute decision-maker (Health Care Consent Act, 1996, s. 20(1)). The parents, being equally ranked on the hierarchy must make a joint decision; in cases where there is disagreement the Public Guardian and Trustee makes a decision in their stead (Health Care Consent Act, 1996, s. 20(5–6)). While there are no age distinctions with respect to consent to one's own treatment, there is an age distinction employed in consenting on an incapable person's behalf: substitute decision-makers must be over 16 years of age, capable, available, and willing to assume responsibility (Health Care Consent Act, 1996, s. 20(2)).

3.4.2 The Substitute Decisions Act (1992)

Age distinctions are likewise present with respect to making decisions on behalf of others under the Substitute Decisions Act (1992), which governs the delegation of decisions about property and personal care to another individual. While authority as an attorney for personal care to make decisions about treatment, admission to a care facility, and personal assistive service is outlined in the Health Care Consent Act, the Substitute Decisions Act provides guidelines for creating a power of attorney for property and/or personal care. The Power of Attorney for Personal Care is a document to appoint an individual as your attorney to make personal care decisions on your behalf (Queens Printer for Ontario, 2012, p 9). Personal care decisions include decisions relating to health care, nutrition, shelter, clothing, hygiene, and safety (Byrick and Walker-Renshaw, 2016, 3-5). Persons must be over 16 years of age in order to create a power of attorney for personal care, and to exercise the power of decisions on behalf of other persons (Substitute Decisions Act, 1992, s. 43–44). The Continuing Power of Attorney for Property is a document to appoint an individual as your attorney to make decisions about your property and to manage your finances on your behalf (Queen's Printer for Ontario, 2012, p 4). Under the Substitute Decisions Act, a person must be over 18 years of age to be

²¹ A parent with only right of access is ranked lower on the hierarchy (a parent with only right of access is sixth whereas a parent is ranked fifth on the substitute decision-maker hierarchy).

eligible to create a power of attorney for property (Substitute Decisions Act, 1992, s. 4). In addition, the Substitute Decisions Act outlines provisions for a court-appointed Guardian for Property (1992, s. 22(1)). The SDA also enables Statutory Guardianship where the Public Guardian and Trustee may be involved in the management of property on behalf of an incapable person (Byrick and Walker-Renshaw, 2016, 3-6).

3.4.3 The Mental Health Act (1990)

Age distinctions are also employed under the law regarding informal admission to a psychiatric facility. The Mental Health Act (1990) guides admissions to psychiatric facilities and guides the management of psychiatric out-patients under Community Treatment Orders (Byrick and Walker-Renshaw, 2016, 1-6). The Mental Health Act also defines the criteria for voluntary, informal, and involuntary admissions to specially designated psychiatric facilities (Byrick and Walker-Renshaw, 2016, 1-6). A voluntary patient is a person who has agreed to be admitted to a psychiatric facility for care, observation, and treatment (Byrick and Walker-Renshaw, 2016, 3-5). The Mental Health Act defines an informal patient as a patient who is admitted with the consent of another person under s. 24 of the Health Care Consent Act (Byrick and Walker-Renshaw, 2016, 3-5). An involuntary patient is a person who has been assessed by a psychiatrist and meets the criteria to be admitted and detained as a patient involuntarily. A person's status under the Mental Health Act can change throughout the course of their hospital admission.²²

The Mental Health Act also regulates informal admission of a patient to a psychiatric facility with the consent of another person under s. 24 of the Health Care Consent Act (Byrick and Walker-Renshaw, 2016, 3-5). Informal admissions give authority to a substitute decision-maker to give consent to admission on an incapable patient's behalf, and typically involves parents consenting to admitting their child or adolescent to a psychiatric facility (Byrick and Walker-Renshaw, 2016, 3-5). Ages 12 and 16 shift decision-making authority under the Health Care Consent Act in cases of informal admission. Between 12 and 16 years of age, a patient informally admitted to a psychiatric

²² A person can be admitted involuntarily, then authorized to continue their admission as a voluntary or informal patient before the authorized period of detention has expired (Byrick and Walker-Renshaw, 2016, 3-3). Conversely, a person may be admitted voluntarily or informally, and then may experience a change in their condition such that they are found to meet the criteria for involuntary admission (Byrick and Walker-Renshaw, 2016, 3-3).

facility has recourse to apply to the Consent and Capacity Board²³ to determine whether they need observation, care, or treatment in a psychiatric facility (Byrick and Walker-Renshaw, 2016, 3-5). Meanwhile, a person over 16 years of age who objects to being admitted to a psychiatric facility for treatment of a mental disorder can only be informally admitted in a narrower set of circumstances (Byrick and Walker-Renshaw, 2016, 3-5). Consent for informal admission of a minor over 16 may only be given by the patient's guardian of the person or their attorney for personal care in cases where they are given express authority in the respective authorizing documents (Byrick and Walker-Renshaw, 2016, 3-5).

3.4.4 The Child, Youth and Family Services Act (2017)

3.4.4.1 Child Protection and Consent to Treatment

In the context of treatment, children have rights under ss. 3 and 8(1)(a) of the Child, Youth and Family Services Act. Under ss. 3 and 8(1)(a), children have the right to express own views freely and safely about matters that affect them; the right to engage in honest and respectful dialogue about how and why treatment decisions affecting them are made; and rights to be consulted and participate in treatment decisions, raise concerns and recommendations with respect to treatment, have their views given due weight in accordance with their age and maturity, and to be advised of treatment decisions (Child, Youth and Family Services Act, 2017). Lastly, children have the right to be informed of their rights under s. 3 of the Act (Child, Youth and Family Services Act, 2017).

The Child, Youth and Family Services Act defines a child requiring treatment in terms of the following. The child must require a treatment to cure, prevent, or alleviate physical or (risk of) emotional harm or suffering. Further, the parent or person having charge of the child does not provide services, treatment, or access to services or treatment. Alternatively the child is incapable of consenting to treatment under the Health Care Consent Act and the parent or substitute decision-maker refuses or is unavailable to consent to treatment for the child (2017, s. 74(2)). Protection is likewise required for a child in a similar scenario where they are suffering from a mental, emotional, or developmental condition that, if not remedied, will impair child development, or where services or

²³ In Ontario, the Consent and Capacity Board is an independent provincial tribunal for conducting the fair and accessible adjudication of capacity, consent, civil committal, and substitute decision-making to balance the rights of vulnerable individuals with public safety. The CCB will be discussed in more detail in Chapter 5.

treatment are required to prevent a recurrence of significant harm to others (Child, Youth and Family Services Act, 2017, s. 74(2)).²⁴

Provincial and territorial child protection legislation for healthcare consent is generally triggered when a parent or guardian refuses or neglects to consent to necessary care (Council of Canadian Academies, 2018, p 51). In cases where a child is in need of protection as a result of a parental refusal to consent to treatment, a temporary care agreement can be made to transfer parental authority to consent to treatment to the Children's Aid Society, ranging from 5 to 21 days (Child, Youth and Family Services Act, 2017, s. 74(2)). In some circumstances, the court may authorize the Children's Aid Society to act in place of the parent in providing consent to treatment on the child's behalf (Child, Youth and Family Services Act, 2017, s. 74(2)). The Children's Aid Society may also provide consent to treatment on behalf of a child who is in interim society care (a period under one year) by court order, though the court may order that the parent retain their authority to give or refuse treatment on behalf of the incapable child (Child, Youth and Family Services Act, 2017, s. 74(2)).

Although the Child, Youth and Family Services Act authorizes a parent or the Children's Aid Society to give, withhold, or withdraw consent on behalf of the child, the Act specifies that such authorization does not override capable children's decisions about treatment made in accordance with the Health Care Consent Act. In fact, subsection (3) of s. 301 states that the decision of a capable child to give or withhold consent to treatment prevails over a conflicting decision by the substitute decision-maker (Child, Youth and Family Services Act, 2017). Yet, in cases where a minors refuses necessary treatment, it is unclear to what extent welfare considerations may challenge the law's commitment to respecting the self-determination and autonomy interests of mature minors (Council of Canadian Academies, 2018, p 39). This will be discussed in more detail later in this chapter, in analyzing mature minor consent and refusal of treatment in case law.

3.4.4.2 Duty to Report

Health care providers²⁵ have a duty to report to the Children's Aid Society where they have reasonable grounds to suspect harm or impending harm to the child, inadequate provisions for care and custody, or unencumbered risk of significant recurrent harm to others (Child, Youth and Family

²⁴ Conditions include where the child is younger than 12 and has killed or seriously injured another person or caused serious damage to another person's property (Child, Youth and Family Services Act, 2018, s. 74(2)).

²⁵ Under the Act, health care providers include physicians, nurses, dentists, pharmacists, and psychologists (Child, Youth and Family Services Act, 2018, s. 125).

Services Act, 2017, s.125). Suspected harm or impending harm to the child includes physical harm or emotional harm demonstrated by serious anxiety, depression, withdrawal, self-destructive or aggressive behaviour, or delayed development resulting from a pattern of neglect or failure of adequate care of, provision for, and supervision and protection of the child (Child, Youth and Family Services Act, 2017, s. 125). Suspected harm or impending harm may also include actual or possible sexual abuse or exploitation, where the person having charge of the child is aware of it and fails to protect the child (Child, Youth and Family Services Act, 2017, s. 125). Further, there is a duty to report where a child is in need of protection or is imminently in need of protection as a result of a parent or the person charged with the child refusing or being unwilling to consent to treatment (Child, Youth and Family Services Act, 2017, s.125).

3.4.4.3 Secure Treatment Program

A physician may also make an application to admit a child who is over 16 years of age to a secure treatment program under the Child, Youth and Family Services Act for no longer than 30 days (2017, s. 158, 161).²⁶ A secure treatment program is a program admitted under court order for the treatment of a child with a mental disorder where continuous restrictions are imposed on the liberty of the child (Child, Youth and Family Services Act, 2017, s. 158). Criteria for admission to the program include that the child has a mental health disorder and has recently (within 45 days) been detained under the Youth Criminal Justice Act or admitted as an involuntary patient under the Mental Health Act; the child must also have caused or attempted to cause serious bodily injury to themselves or to another person (Child, Youth and Family Services Act, 2017, s. 164). Another condition of the program is that, within the last year, the child has on another occasion caused or attempted a substantial threat to cause serious bodily harm or death to themselves or others (Child, Youth and Family Services Act, 2017, s. 164). Further, the program would be effective to prevent a child from causing or attempting serious bodily harm to themselves or others, appropriate treatment for the child's mental health disorder is available at the program, and there is no less restrictive method of providing treatment appropriate in the circumstances (Child, Youth and Family Services Act, 2017, s. 164). A child over 16 may make an application for admission (Child, Youth and Family Services Act, 2017, s. 161).

²⁶ Physicians cannot make an application to admit children under 16 to secure treatment programs (Child, Youth and Family Services Act, 2017, s. 158, 161). Furthermore, they cannot extend treatment unless the child is over 18 years of age and provides written consent (Child, Youth and Family Services Act, 2017, s. 167(2)(c)).

3.5 Summary

Ontario's statutory law generally promotes the decision-making authority and self-determination of capable minors by allowing them to make their own treatment decisions. Yet there is some fluctuation in this authority under provincial legislation depending on their capacity and the nature of the decision. This can be challenging where a mature minor's capacity is uncertain, which can obscure the appropriate response under the legal framework. In addition, mature minor authority is influenced by other factors: whether the decision is current, made in advance, made on their own behalf, or made on behalf of another.

Furthermore, there are certain limitations to mature minor self-determination under statutory law. For instance, minors under 16 may be informally admitted for psychiatric treatment despite objecting to the admission, and minors under 18 may be admitted by another individual to a secure treatment program under exceptional circumstances. The law also functions to protect children's welfare in scenarios where treatment is required to alleviate physical or emotional harm, suffering, or developmental impairment to the child development, or to prevent a recurrence of significant harm to others. Health care professionals have a duty to report to the Children's Aid Society where there are reasonable grounds to suspect harm or impending harm to the child – this includes cases of parental refusal to consent to necessary treatment. In the interests of protecting a child's welfare, the law gives authority to the Children's Aid Society to override the wishes of a parent in cases where they refuse to consent to necessary treatment. This authorization does not override that of mature minors to consent to their own treatment, yet at the same time mature minor authority is not absolute. The following sections will consider case law regarding mature minor decision-making, including cases where child protection legislation is engaged when a minor refuses necessary treatment.

3.6 The Rights of Self Determination and Inviolability under the Common Law

The following sections provide an analysis of jurisprudence to inform interpretation of children's rights under the common law, when they have 'mature minor' status (i.e., they are capable of consenting to treatment but have not yet reached the age of majority). Both patient rights to self-determination and inviolability, and the state's obligation to protect youth as vulnerable persons are established in Canadian common law. *Malette v. Shulman*, *Fleming v. Reid*, and *R. v. Morgentaler* provide legal precedent in establishing rights to self-determination and inviolability in the common law, as well as s. 7 rights to security of the person under the Charter. In *Malette v. Shulman* (1990), the Court of Appeal for Ontario considered whether a physician committed battery by administering a life-saving blood transfusion to an unconscious patient against their known religious convictions.²⁷ The physician was found by the courts to have acted honestly on his professional judgement and responsibility, and the trial judge argued that he managed the case competently, carefully, and conscientiously in accordance with the requisite standard of care (*Malette v. Shulman*, 1990, p 8). Yet the physician was liable in the trial court for tortiously violated his patient's rights over her own body (*Malette v. Shulman*, 1990, p 8). Delivering the judgment on behalf of the Court of Appeal for Ontario, Robins JA sided with the trial judge by concluding that the "interest in the freedom to reject, or refuse to consent to, intrusions of her bodily integrity — outweighs the interest of the state in the preservation of life and health and the protection of the integrity of the medical profession" (*Malette v. Shulman*, 1990, p 19).²⁸

One year later, an order from a review board authorizing the treatment of involuntary psychiatric patients with schizophrenia was successfully appealed at the Court of Appeal for Ontario on the basis of patient rights to self-determination and inviolability in *Fleming v. Reid* (1991). The Court of Appeal for Ontario argued that the common-law principle that every competent adult has the right to be free from unwanted medical treatment extends to mentally competent patients in psychiatric facilities (*Fleming v. Reid*, 1991, p. 3). As such, physicians are not free to disregard patients' advance

²⁷ The patient carried a card she signed that identified her as a Jehovah's Witness, and articulated her request not to be given a blood transfusion under any circumstances due to her religious convictions (*Malette v. Shulman*, 1990, p. 2). Further, the patient's daughter confirmed her mother's wishes by seeking to terminate the transfusions, but the physician refused to follow her instructions (*Malette v. Shulman*, 1990, p. 2).

²⁸ Interestingly, Robins JA distinguishes the refusal of life sustaining treatment from the issue of physician assisted death/suicide by claiming that "the interest of the state in protecting innocent third parties and preventing suicide are ... not applicable to the present circumstances" (*Malette v. Shulman*, 1990, p. 19).

instructions expressing refusal to consent to treatment in anticipation of circumstances where they are unconscious or otherwise incapacitated (Fleming v. Reid, 1991, p. 3). Further, the court of appeal determined that “the common law right to determine what shall be done with one’s own body and the constitutional right to security of the person can be treated as co-extensive” (Fleming v. Reid, 1991, p. 3) – meaning they refer to one another.

The reasoning used to connect rights to bodily integrity and s. 7 rights to security of the person is also established in SCC judgments. In *R. v. Morgentaler* (1988), the prohibition of abortion (s. 251 of the Criminal Code) was successfully challenged on the basis of the s. 7 Charter right to security of the person of pregnant women (*R. v. Morgentaler*, 1988, p 79h–i). Part of the SCC judgment invokes the common law’s long recognition “that the human body ought to be protected from interference by others” (*R. v. Morgentaler*, 1988, p 53g) – which entails that any medical procedure carried out on a person without their consent is an assault (*R. v. Morgentaler*, 1988, p 53g–h). Further, the SCC concludes that “state interference with bodily integrity and serious state-imposed psychological stress, at least in the criminal law context, constitute a breach of security of the person” (*R. v. Morgentaler*, 1988, p 56b). The right to bodily integrity was also elaborated on in *Ciarlariello v. Schacter* (1993) and *Nightingale v. Kaplovich* (1989), where the SCC justifies the right to withdraw consent during the course of a medical procedure. They argue that the duty to stop medical procedures where the patient withdraws consent is based on the recognition that every individual has a basic right to make decisions concerning their own body (*Ciarlariello v. Schacter*, 1993, p 136d–e).

Thus, common-law precedent affirms that rights to personal liberty and bodily integrity outweigh the state’s interests to preserve life protect the integrity of the medical profession. This right to bodily integrity makes claims on physicians not to disregard patient wishes, including advance directives. Patients have a right to be free from unwanted medical treatment, including cases of mentally capable patients in a psychiatric facilities, and patients who withdraw their consent to treatment. State interference with a patient’s bodily integrity constitutes a breach of security of the person under s. 7, including serious state-imposed psychological stress.

3.7 Mature Minors' Healthcare Decisions under the Common Law

3.7.1 *Gillick v. West Norfolk and Wisbech Area Health Authority* (1985)

The “mature minor” principle was adopted by the Canadian courts from the British House of Lords, which articulated the principle in *Gillick v. West Norfolk and Wisbech Area Health Authority* (1985). The House of Lords ruled that adolescents under 16 can consent to medical treatment in their judgment concerning whether a doctor could prescribe contraception for a girl under 16 without the consent of her parents without attracting liability in tort (AC v. Manitoba, 2009, par. 48-49). The majority argued that, upon being found capable of understanding the proposed treatment and expressing their own wishes, minors under 16 are also capable of expressing those wishes and authorizing treatment. They further claimed that these capabilities are indicated by minor’s known capabilities under the law, including entering into a contract, to sue and be sued, giving evidence on oath, and consenting to sexual intercourse (AC v. Manitoba, 2009, par. 49). This ruling established the concept of the “Gillick competent child,” who can give consent as effectively as an adult and cannot be overruled by a parent (Griffith, 2016, p. 245).

Gillick competency reflects the transition of a child to adulthood. Assessing whether a child is Gillick competent involves examining the child’s process in making a decision, taking into consideration the maturity and intelligence of the child according to the seriousness and complexity of the treatment decision (Griffith, 2016, p. 244-5). Judgment of the child’s maturity is based on the child’s experience, and their “ability to manage influences on their decision making including information, peer pressure, family pressure, [and] fear and misgivings” (Griffith, 2016, p 245). Meanwhile, intelligence is based on the child’s “understanding, ability to weigh risk and benefit, consideration of longer term factors such as effect on family life and on such things as schooling” (Griffith, 2016, p 245). In the context of child and adolescent health decisions, the required maturity and intelligence to be Gillick competent is a matter of degree, dependent on the gravity of the decision (Griffith, 2016, p 245). More complex decisions require a greater level of competence and a higher level of understanding, and are more likely to overwhelm a child who lacks sufficient maturity (Griffith, 2016, p 245). This framing of Gillick competency as a matter of degree is compatible with conceptions of consent under statutory law under the Health Care Consent Act, where consent is time and treatment specific such that patients can be capable of making some health care decisions while incapable of making other decisions.

3.7.2 *J.S.C v. Wren* (1986)

Gillick competency was introduced to the Canadian courts through *J.S.C. v. Wren* (1986) at the Alberta Court of Appeal. In this case, the parents of a 16-year-old girl who received approval for an abortion by a statutory committee launched a suit against her physician (*J.S.C. v. Wren*, 1986, par. 5–6). In their appeal, the parents contested the trial judge’s finding that their child was capable of giving informed consent (*J.S.C. v. Wren*, 1986, par. 8–9). In their ruling, the Alberta Court of Appeal addressed the issue of parental control of Gillick competent children. They claimed that while parental rights do not fully disappear until the age of majority, the courts will exercise increasing restraint on those rights “as a child grows to and through adolescence” (*J.S.C. v. Wren*, 1986, par. 13). Applying this reasoning to the issue of medical treatment, the Alberta Court of Appeal determined that parental rights terminate when the child has sufficient understanding and intelligence to enable them to understand fully what is proposed (*J.S.C. v. Wren*, 1986, par. 14).

3.7.3 *Van Mol v. Ashmore* (1999)

The principle of autonomous self-determination was also applied to mature minors by the British Columbia Court of Appeal in *Van Mol v. Ashmore* (1999). Following a rare complication of a heart surgery, a 16 year old plaintiff and her parents brought an action in negligence against her doctor and surgeon. One basis of their claim was that the surgeon failed to obtain informed consent as he did not disclose risks associated with the surgery, and did not permit the plaintiff’s participation in the decision (*Van Mol v. Ashmore*, 1999, par. 4). The British Columbia Court of Appeal ruled the trial judge erred in identifying the plaintiff’s parents as the agents who must give informed consent, arguing instead that the plaintiff must give informed consent. They claimed that once a young person has achieved the required capacity to consent, they hold all rights in relation to giving or withholding consent – including the discussion and decision process (*Van Mol v. Ashmore*, 1999, par. 75). Further, the British Columbia Court of Appeal confirmed that parents or guardians of mature minors no longer have “any overriding right to give or withhold consent” (*Van Mol v. Ashmore*, 1999, par. 75). Hence, in addition to recognizing patient decision-making authority and rights of the patient to bodily integrity, the common law also guides the decision-making authority of children. This is understood through the concept of the Gillick competent child, a capable child who can give consent as effectively as an adult, and cannot be overruled by a parent.

3.8 Adolescent Refusals of Life-Saving Treatment under the Common Law

3.8.1 *Re: R (A Minor) (Wardship: Consent to Treatment) (1991)*

While the adoption of Gillick competency into Canadian common law entrenched children's rights to self-determination, it does not reclassify mature minors as adults for the purpose of treatment decisions (AC v. Manitoba, 2009, par. 52, 56). Two cases ruled by the English Court of Appeal found considerations of self-determination to be outweighed by considerations of welfare. In 1991, the question on the permissibility of administration of an anti-psychotic medication to an adolescent patient who refuses to consent to the treatment was considered in *Re R (A Minor) (Wardship: Consent to Treatment) (1991)*. R was a 15-year-old adolescent who was received into voluntary care of her local authority following a fight with her father (Sandland, 1992, p 145). After her local authority assumed R's care, her mental health deteriorated and she was placed in an adolescent psychiatric unit (Sandland, 1992, p 145). One evening R entered into a psychotic state, requiring the administration of an anti-psychotic medication, for which R's local authority provided consent (Sandland, 1992, p 145). This consent was retracted upon R contacting the local authority to inform them that she was unwilling to consent to the treatment (Sandland, 1992, pp 145–146). Over the following month, R's condition remediated to the stage where she was found to be capable, yet the senior consultant at the unit believed that without the treatment, "her more florid psychotic state is likely to return" (Sandland, 1992, p 146). On the basis of this disagreement with R's refusal, the unit "refused to provide continued care to R unless they could be guaranteed a free hand" (Sandland, 1992, p 146). The courts were involved to resolve the disagreement (Sandland, 1992, p 146).

The High Court ordered that the treatment proceed without R's consent (Sandland, 1992, p 146). The High Court judge found that exercising wardship jurisdiction could not override the wishes of a competent minor (Sandland, 1992, p 146). Yet the judge determined in applying the assessment of a Gillick competent child that R did not have a sufficient degree of maturity and understanding to provide consent to the treatment (Sandland, 1992, p 146).

The English Court of Appeal upheld the ruling, affirming R's incapability to consent to the administration of an anti-psychotic medication (Sandland, 1992, p 146). Moreover, among

positioning various other points,²⁹ the Court of Appeal held that the court can overrule a Gillick competent child's wishes if they are under wardship jurisdiction (i.e., legal guardianship of the High Court) (Sandland, 1992, p 146). Lord Justice Farquharson justified this principle by characterizing the simple application of the welfare principle as the task of the judiciary in deciding questions about the upbringing of a ward (Sandland, 1992, p 146). Meanwhile, Lord Justice Donaldson attributed the overriding authority of the courts over a minor's wishes to a wider practical jurisdiction of a court of wardship, based in duties of the Crown to protect subjects, than the jurisdiction of parents, based in duties of parental rights and responsibilities (Sandland, 1992, p 147). Moreover, in his interpretation of Gillick competency, Lord Justice Donaldson narrowed the authority of Gillick competent children to situations of providing consent to treatment (such that the parents cannot veto their decision) (Sandland, 1992, p 147). Under this interpretation, a Gillick competent child's authority may not outweigh parental authority in situations where the child refuses treatment, but co-exists with parental authority (Sandland, 1992, p 147).

3.8.2 *Re W (A Minor) (Medical Treatment: Court's Jurisdiction) (1992)*

The English Court of Appeal also considered the question of adolescent's refusal of treatment in *Re W (A Minor) (Medical Treatment: Court's Jurisdiction)* (1992). W was a 16-year-old adolescent whose observed behaviours were consistent with a diagnosis of anorexia nervosa (Sandland, 1993, p 138). After a period of outpatient treatment, W was admitted to a residential unit specializing in the treatment of minor patients with psychiatric disorders, but upon further decline in her condition it was determined that W should be transferred to another hospital with an in-patient eating disorders unit (Sandland, 1993, p 138). W refused consent to the new treatment plan, and although W was found to have sufficient understanding to make an informed decision, the court authorized treatment to proceed despite W's refusal of treatment (Sandland, 1993, p 138).

²⁹ The justices gave some guidance on who can give, refuse, or veto consent for the proposed treatment of a competent minor (Sandland, 1992, p 147). There was further discussion on assessment of maturity, where Lord Justice Donaldson held that a Gillick competent child must exhibit an actual understanding and appreciation (rather than a potential understanding) of the treatment, any possible side effects, and the failure to treat (Sandland, 1992, p 149). Moreover, on the issue of R's capacity, Lord Justice Donaldson asserted that even were R found to be capable on a good day of sufficient understanding, she would be sectionable on a bad day, and therefore cannot be Gillick competent (Sandland, 1992, p 150). Lord Justice Farquharson also differentiated between sectionable and non-sectionable minors in his analysis of Gillick competency (Sandland, 1992, p 150). This raises questions of whether a sectionable minor could ever be found to be capable (Sandland, 1992, p 150).

The High Court judge ruled that the court's inherent jurisdiction includes a power to override the W's wishes as a minor, given the evidence that the proposed transfer and treatment were in her best interests (Sandland, 1993, pp 138–139). W appealed the decision, arguing that the statutory right to consent treatment under s. 8 the Family Law Reform Act (1969) supersedes the High Court's inherent jurisdiction. Further, in the case that the court's inherent discretion did apply to a minor's refusal of treatment, then W's case was an inappropriate case in which to exercise the court's discretionary powers to overrule the wishes of a competent minor (Sandland, 1993, p 139).

The English Court of Appeal dismissed W's appeal, ruling that even a Gillick competent minor was subject to the court's inherent *parens patriae* jurisdiction, especially in situations where the child's life is threatened (AC v. Manitoba, 2009, par. 54). Where s. 8 of the Family and Child Services Act affirmed the child's authority in consenting to treatment, it was silent on cases where a child refuses treatment (Sandland, 1993, p 140). Since Gillick competent children are subject to *parens patriae* jurisdiction, the court has the power to authorize treatment of a Gillick competent child according to their best interests (AC v. Manitoba, 2009, par. 55). Yet the English Court of Appeal also determined that an assessment of the child's "best interests" must take into account their wishes and objections, where deference to these views varies according to the child's maturity (AC v. Manitoba, 2009, par. 55).

The cases of *Re R* and *Re W* retreated from the legal recognition in the Gillick decision of mature minor rights to self-determination and mature minors' authority to make decisions relative to parental and state authority (Sandland, 1992, p 151). These rulings cast uncertainty in jurisprudence (Sandland, 1992, p 152), particularly with respect to state authority to enact *parens patriae* jurisdiction in order to intervene in a mature minor's decision for the purpose of protecting their welfare. *Parens patriae*, welfare, and best interests will be discussed in more detail in Chapter 5 of this dissertation.

3.8.3 AC v. Manitoba (2009)

In spite of conflicting principles delivered in the judgments of *Gillick v. West Norfolk and Wisbech Area Health Authority* (1985), *Re R (A Minor) (Wardship: Consent to Treatment)* (1991), and *Re W (A Minor) (Medical Treatment)* (1992), recent judgments in the Canadian courts have upheld mature minor authority. The SCC gave a ruling on the judgment of *AC v. Manitoba* (2009), where a mature minor refused life-saving treatment. In *AC v. Manitoba*, a 14-year-old adolescent referred to as C, a devout Jehovah's Witness, was admitted to hospital suffering from lower gastrointestinal bleeding caused by Crohn's disease (AC v. Manitoba, 2009, p. 183). Despite her doctor's belief that internal

bleeding created “imminent, serious risk to her health and perhaps her life” (AC v. Manitoba, 2009, p 183), she refused to consent to receiving blood on religious grounds, and signed an advance medical directive containing her written instructions not to be given blood under any circumstances (AC v. Manitoba, 2009, p. 183). In response, the director of Child and Family Services apprehended C as a child in need of protection, seeking a treatment order from the court under section 25(8) of Manitoba’s Child and Family Services Act (AC v. Manitoba, 2009, p. 183). Section 25(8) allows the courts to authorize treatment considered to be in the child’s best interests (AC v. Manitoba, 2009, p 183). Provincial appellate courts had previously held in the provinces of British Columbia, Alberta, and Manitoba, that the child protection legislation displaced the common-law mature minor doctrine. As a result, child welfare authorities could be authorized to consent to treatment in cases where the minor was decisionally capable and refused necessary treatment (Gilmore, 2011, p 390).

In court, the applications judge ordered that C receive blood transfusions (AC v. Manitoba, 2009, p. 158). Further, the applications judge ruled on the subject of Section 25(9) of the Manitoba Child and Family Services Act, which presumes that the best interests of children over 16 are most effectively promoted by the child’s own views being determinative (under the age of 16 there is no such presumption) (AC v. Manitoba, 2009, p. 24). Though C underwent a brief psychiatric assessment the night after her admission, the judge ultimately ruled that under the age of 16, there are “no legislated restrictions of authority on the court’s ability to order medical treatment in the child’s ‘best interests’” (AC v. Manitoba, 2009, p. 12).

C and her parents appealed the applications judge’s order. They argued that ss. 25(8) and 25(9) of the Manitoba Child and Family Services Act were unconstitutional because they unjustifiably infringed C’s rights under ss. 2(a), 7, and 15 of the Canadian Charter of Rights and Freedoms. In C’s case in particular, she was no longer under the age of 16 at the time of the SCC judgement and her maturity was not assessed in prior court proceedings (AC v. Manitoba, 2009, par. 120). Reaching the SCC, C and her parents lost their constitutional challenge, and their appeal was dismissed (AC v. Manitoba, 2009, par. 121). Where the “best interests” standard is interpreted such that minors have the opportunity to prove that they have decision-making capacity, the majority for the SCC agreed with the Court of Appeal that ss. 25(8) and 25(9) of the Child and Family Services Act are neither arbitrary nor discriminatory, nor do they violate religious freedom (AC v. Manitoba, 2009, p 183).

Despite C’s appeal being dismissed, she succeeded on the applicable principle (Gilmore, 2011, p 391). C successfully argued that ss. 25(8) and 25(9) of the Child and Family Services Act should be

interpreted such that the medical treatment decisions of adolescents under 16 must be respected where they demonstrate sufficient maturity (AC v. Manitoba, 2009, par. 121). As such, the SCC rejected the interpretation that child protection legislation could authorize overruling mature minor authority to make their own treatment decisions (Gilmore, 2011, p 390). This was a landmark decision, as the courts ruled that capable minors can refuse life-sustaining treatments. An important aspect of this judgment was that the Supreme Court of Canada recognized mature minors' capacity to be self-governing through their interpretation of the "best interests" standard such that minors have the opportunity to prove that they have decision-making capacity. This recognition of minors' capacity to self-govern extends to life-and-death decisions.

3.8.4 The Cases of Makayla Sault, and JJ (*Hamilton Health Sciences Corp. v. D.H.* (2014))

While it did not result in jurisprudence on the mature minor principle specifically, value tensions in a mature minor's right to refuse treatment were reignited in 2014 by a pair of cases in which Indigenous minors, Mikayla Sault and JJ, refused chemotherapy. Makayla Sault was an 11-year-old minor from the Mississauga-Ojibwe reserve of New Credit First Nation who was living with acute lymphoblastic leukemia (Murray and Lemieux, 2016, p 91). Makayla had been undergoing a series of chemotherapy treatments at McMaster Children's Hospital until she reported a spiritual experience which led her to withdraw from treatment with the intention of pursuing Indigenous medical therapies administered by a traditional healer on the Six Nations (Murray and Lemieux, 2016, p 91). As the medical team felt Makayla was refusing life-saving treatment, they reported her case to the local Children's Aid Society to determine her capacity to refuse continued chemotherapy treatments (Murray and Lemieux, 2016, pp 91, 93). The local Children's Aid Society deemed Makayla capable to refuse treatment, and no further legal actions were taken against her and her family (Murray and Lemieux, 2016, p 93). Makayla died at home the following year after suffered a fatal stroke (Murray and Lemieux, 2016, p 104).

Later in 2014, a similar case arose in *Hamilton Health Sciences Corp. v. D.H.* (2014), where a hospital brought an application to under Ontario's former Child and Family Services Act³⁰ against the local Children's Aid Society. In the case, an 11-year-old girl from The Six Nations of the Grand River named JJ refused chemotherapy (*Hamilton Health Sciences Corp. v. D.H.*, 2014, par. 1–2). JJ had

³⁰ Ontario's Child and Family Services Act was replaced by the Child, Youth and Family Services Act in 2017.

been diagnosed with acute lymphoblastic leukemia (a form of cancer in the bone marrow), treatment for which involved the delivery of chemotherapy in a number of phases which offered a 90–95% chance that JJ would be cured (Hamilton Health Sciences Corp. v. D.H., 2014, par. 2). Meanwhile, forgoing treatment would likely remove any chance of cure, and JJ would likely die of a curable condition: the specialist team were unaware of any survivors of acute lymphoblastic leukemia without chemotherapy treatments (Hamilton Health Sciences Corp. v. D.H., 2014, par. 2, 12). The medical team determined that JJ was incapable of giving informed consent to withdraw from therapy and was hence not a mature minor with respect to this treatment decision (Hamilton Health Sciences Corp. v. D.H., 2014, par. 12). JJ commenced chemotherapy treatment but JJ’s mother had the treatment discontinued two weeks later with the plan to treat JJ with traditional medicines and alternative treatments in Florida (Hamilton Health Sciences Corp. v. D.H., 2014, par. 3, 8–12, 15).

JJ’s attending physician reported the refusal of treatment to Children’s Aid Society, as they felt this decision to terminate chemotherapy puts JJ’s life at risk (Hamilton Health Sciences Corp. v. D.H., 2014, par. 11–12). Aware of JJ’s mother’s plans, the local Children’s Aid Society advised the attending physician that they had no plans to intervene (Hamilton Health Sciences Corp. v. D.H., 2014, par. 16). The issue was brought before the Ontario Court of Justice, where an order was made that JJ not be removed from the province of Ontario without further order from the court – yet near or at the first return of the application, JJ and her mother had already departed to Florida and declined to return (Hamilton Health Sciences Corp. v. D.H., 2014, par. 6, 25).

In their judgment, the Ontario Court of Justice centred the issue on the question of whether JJ was a child in need of protection under the former Child and Family Services Act (Hamilton Health Sciences Corp. v. D.H., 2014, par. 54). In particular, the decision considered whether JJ needed protection as a child requiring medical treatment to cure, prevent, or alleviate physical harm or suffering, where the child’s parent or person having charge of the child does not provide or refuses or is unavailable or unable to consent to the treatment (Hamilton Health Sciences Corp. v. D.H., 2014, par. 56). The court concluded that JJ was not a child in need of protection, as her mother’s decision to pursue traditional medicine for her daughter was her Aboriginal right under s. 35(1) of the Constitution Act (1982), which states that “the existing Aboriginal and treaty rights of the Aboriginal peoples of Canada are hereby recognized and affirmed” (Hamilton Health Sciences Corp. v. D.H., 2014, par. 60, 81, 83). In 2015, the ruling was amended to qualify that in law and practice the Haudenosaunee have both an Aboriginal right to traditional healthcare and the same right as other

Ontarians to available healthcare (*Hamilton Health Sciences Corp. v. D.H.*, 2015, par. 83b). Accordingly, the right to use traditional medicine must both remain consistent with the “best interests of the child,” and must be considered, among other factors, in analyzing a child’s best interests (*Hamilton Health Sciences Corp. v. D.H.*, 2015, par. 83a). Thus, both cases show important insights regarding adolescents and consent to treatment. The case of Mikayla Sault reinforces the legal framework recognizing that capable children have decision-making authority, including refusing life-sustaining treatment. Further, *Hamilton Health Sciences Corp. v. D.H.* (2014) determined that a patient or SDM’s decision to pursue traditional Indigenous medicine is an Aboriginal right under s. 35(1) of the Constitution Act (1982) and must remain consistent with a child’s best interests, among other factors.

3.9 Conclusion

In conclusion, in the context of healthcare decision-making, the conceptual tensions in mature minor autonomy are likewise present in the legal landscape: in particular, conflicting values of welfare and self-determination. The majority of Canadian provinces and territories do not specify an age of consent to treatment. Where an age of consent is specified (14 or 16), it is below the age of eligibility for MAiD (18). Ontario's statutory law generally promotes the decision-making authority of capable minors, but imposes certain limitations in the interests of their welfare. Child protection legislation is highly responsive to actual or impending harm to a child, including refusal of consent to necessary treatment.

The question of the authority of the courts and child-welfare authorities in overriding a mature minor's consent or refusal of consent to treatment has been contemplated in the common law. Canadian common-law jurisprudence has adopted the "mature minor" principle, based on the concept of the Gillick competent minor as articulated in English common law: capable adolescents under 16 can consent to medical treatment as effectively as an adult and cannot be overruled by a parent. Yet uncertainties remain regarding the authority of the state to limit mature minor decisions in order to protect their welfare under *parens patriae* jurisdiction. Recent cases have affirmed mature minors' decision-making authority. *Hamilton Health Sciences Corp. v. D.H.* (2014) interpreted a child in need of protection in a way that recognizes Aboriginal and treaty rights to traditional medicine and health care practices, and included considerations of the right to traditional health care in interpreting the "best interests of the child." Meanwhile, in *AC v. Manitoba* (2009), the SCC rejected interpretations of child-protection legislation to override the authority of mature minors refusing life-sustaining treatment.

Chapter 4

Age Distinction in Canada's Bill C-14: Necessary or Discriminatory?

4.1 Introduction

Under Bill C-14, a condition to be eligible for MAiD is to be at least 18 years old. This chapter considers whether this restriction is justified. The previous chapter provided background on statutory and common law in Canada relating to mature minor capacity, self-determination, and vulnerability with respect to consent to treatment. The consent to treatment of minors is regulated under statutory law, such as Ontario's Health Care Consent Act, the Mental Health Act, and the Child, Youth and Family Services Act. Across the country, legislation varies on the age of consent to treatment. Most provinces defer to the common-law mature minor doctrine or a similar regime, which specifies no age of consent. Quebec allows minors who are at least 14 years old to consent to treatment, and New Brunswick allows minors 16 or older to consent to treatment. In this way, restricting MAiD eligibility to adults at least 18 years of age deviates from most treatments, where the law accommodates younger adolescents to provide consent or does not make an age distinction at all.

Under the common law, there are strong values of empowering autonomy and protecting welfare, as discussed in Chapter 2 of this work. Patients have a right to self-determination and inviolability, protected under s. 7 of the Charter. Furthermore, the autonomy and vulnerability of young people is balanced through the "mature minor principle," which gives guidance that "Gillick competent minors" – that is, minors who are capable of understanding the proposed treatment, have achieved the required capacity, and are expressing their own wishes – can authorize their own treatment. Legal obligations to mature minors expressed through the mature minor principle are also shaped by international legal instruments such as the UN Convention on the Rights of the Child (CRC). Core CRC rights entail duties to act in the best interest of the child, and give consideration to the child's views and wishes. Meanwhile, parents or guardians do not have the right to give or withhold consent on behalf of Gillick competent children. In the case of a mature minor who is withdrawing or withholding life-sustaining treatment, although the court's inherent *parens patriae* jurisdiction may be invoked to limit a mature minor's decision-making authority in order to protect their welfare, the SCC ruled that the treatment decisions of adolescents must be respected where they demonstrate sufficient maturity.

In a case where an adolescent demonstrates capacity and meets all other criteria for eligibility under Bill C-14, the grounds for the legal and ethical rights of mature minors to refuse life-sustaining treatment may also justify mature minors accessing MAiD. Incorporating the legal context from Chapter 3, this chapter analyzes the reasoning which may be employed to challenge the Criminal Code to the degree that it restricts mature minors from accessing MAiD. Opponents of mature minors accessing MAiD would argue that the decision cannot be left in the hands of young people because they cannot grasp the seriousness and consequences of the decision, and that permitting MAiD for mature minors therefore cannot be in the best interests of the child. Under this argument, prohibiting MAiD for mature minors advances the state's interest in protecting children and adolescents who are not sufficiently mature to make an autonomous decision, and further, this protection benefits children and adolescents. This state interference also restricts children from making other fundamental life choices such as attending school, marriage, voting, consenting to sexual intercourse, or selling property.

The chapter explores two lines of argument which counter this position: the challenge that the law may have the effect of shortening life and impinging upon mature minor autonomy by forcing intolerable suffering, and that the exclusion of mature minors from eligibility is an act of age discrimination. After providing some background on s. 7 analysis, this chapter invokes Constance MacIntosh's analysis of Carter and AC, where she argues that a mature minor could claim that Bill C-14 infringes on their s. 7 right to life, liberty, and security of the person using similar reasoning found in the Carter decision. The chapter then turns to analyzing the prospect of a s. 15 challenge that restricting mature minors from MAiD is a case of age discrimination. After reviewing the recent Truchon decision, where claimants successfully challenged the Criminal Code on the basis of discrimination based on physical disability, the chapter then reviews s. 15 analysis and the application of s. 15 to claims of discrimination. Taking into account the reasoning in s. 15 challenges under Carter, AC, and Truchon, the chapter then considers potential arguments that Bill C-14 discriminates against minors on the basis of age – specifically considering whether the law disadvantages mature minors and whether the purpose or effect of the law is ameliorative. Underlying this analysis are two tensions: (1) whether differential treatment on the basis of age is justified as a common and necessary way to order society, and (2) whether the law serves to restrict or to protect mature minor interests.

The analysis ultimately finds a strong case that an age distinction in Bill C-14 disadvantages minors through inaccurate and harmful stereotyping about their ability. This poses an issue of equality

such that minors are unjustifiably treated differently according to their age. Moreover, while it is unclear that the question of an ameliorative purpose is relevant to the case, the law limits the interests of mature minors by having the invidious effect of imposing suffering upon capable minors. Thus, any claims of inequality are not justified by the argument that differential treatment benefits minors. Analysis of s.1 is framed in terms of whether a more permissive regime rather than an absolute prohibition could address risks to mature minors as vulnerable persons. The analysis finds that sufficient safeguarding could protect mature minors from risk of harm, as capable minors have the ability and maturity to make autonomous decision and must be afforded the opportunity to prove their capacity. Eligibility calibrated according to maturity rather than age would adequately address any risks of a vulnerable person being induced to commit suicide in a time of weakness.

4.2 Mature Minors, MAiD, and Section 7 of the Charter

4.2.1 A Brief Overview of s. 7 Analysis

The SCC employs a two-step analysis of engagement of s. 7 rights to life, liberty, and security of the person. The first step asks whether there is an infringement of protected interests in life, liberty, and security of the person (Department of Justice, 2021, web). The right to life is engaged where law or state action directly or indirectly imposes death or an increased risk of death on individuals or groups (Department of Justice, 2021, web). Rights to liberty are engaged either by physical restraint or by state compulsions or prohibitions affecting inherently private choices at the core of personal autonomy, individual dignity, and independence (Department of Justice, 2021, web). The latter protections of autonomous choice include the right to refuse medical treatment and the right to make “reasonable medical choices” without threat of criminal prosecution (Department of Justice, 2021, web). Lastly, the right to security of the person is engaged where the state interferes with personal autonomy and a person’s ability to control his or her own physical, bodily, or psychological integrity (Department of Justice, 2021, web). Where a criminal prohibition forces a person to choose between a legal but inadequate treatment and an illegal but more effective choice, the law will infringe security of the person (Department of Justice, 2021, web). To successfully challenge an impugned provision or government action on the basis of interests protected by s. 7, claimants must establish a “sufficient causal connection” between action/provision and the limit on life, liberty, or security of the person (Department of Justice, 2021, web).

The second step asks whether this deprivation is in accordance with the principles of fundamental justice: that is, sufficiently precise legal principles found in the basic tenets of a fair legal system (according to societal consensus) which yield a manageable standard to measure deprivations of life, liberty, or security of the person (Department of Justice, 2021, web). This stage of the analysis involves two components. First, relevant principles of fundamental justice are identified (Department of Justice, 2021, web). Second, a determination is made whether the deprivation is in accordance with the identified principles (Department of Justice, 2021, web).

Principles of fundamental justice are applied to the objective of the impugned provision in terms of three lines of analysis: arbitrariness, overbreadth, and gross disproportionality (Department of Justice, 2021, web). In *Canada AG v. Bedford*, the SCC contemplated the principles of fundamental justice (arbitrariness, overbreadth, and gross disproportionality), claiming that they qualify our section 7

rights by setting minimum parameters of a law which negatively impacts a person's life, liberty, or security of the person (Canada AG v. Bedford, 2013, par. 94).

A deprivation of a right is arbitrary where it bears no connection to the law's purpose (Department of Justice, 2019, web; *Canada AG v. Bedford.*, 2013, par. 98). For arbitrariness to be engaged, one must demonstrate with evidence that the effect of a law undermines the objective, or that there is no connection between the effect and the objective (Canada AG v. Bedford, 2013, par. 111).

Arbitrariness is exemplified in *R. v. Morgentaler* (1988), where the Supreme Court of Canada considered the question of whether provisions of the Criminal Code which required abortions to be approved by a therapeutic abortion committee of an accredited/approved hospital violated s. 7 of the Charter (Canada AG v. Bedford, 2013, par. 98). The Supreme Court of Canada ruled that the law was arbitrary, as its effects did not contribute to its stated purpose of protecting women's health (Canada AG v. Bedford, 2013, par. 98). In fact, the law contravened its objective by causing delays that were detrimental to women's health (Canada AG v. Bedford, 2013, par. 98). A similar question was considered in *Chaoulli v. Quebec (AG)* (2005), regarding a Quebec law that prohibited private health insurance for services that were available in the public sector. The Supreme Court found that the law was arbitrary, as there was no connection between the law's effects and objective of the law to prevent the diversion of resources from the public health system, based on international evidence that private health insurance and the public health system can coexist (Canada AG v. Bedford, 2013, par. 99). The Supreme Court also determined that the Minister of Health's decision not to extend a safe injection site's exemption from drug possession laws was arbitrary in *Canada (Attorney General) v. PHS Community Services Society* (2011), as the effects of the decision were contrary to the objective of the drug possession laws to protect health and public safety. This was because the services provided by the safe injection site contributed to public health and safety (Canada AG v. Bedford, 2013, par. 100).

Overbreadth describes legislation so broad in scope that it overreaches its purpose and is arbitrary in part by including some conduct that has no rational connection to its purpose (Department of Justice, 2021, web; Canada AG v. Bedford, 2013, 112). For example in *R. v. Heywood* (1994) the Supreme Court ruled that a vagrancy law that prohibited offenders convicted of listed offences from "loitering" in public parks was overbroad (Canada AG v. Bedford, 2013, par. 101). The effect of the law overreached its purpose of protecting children from sexual predators, and was unrelated to its objective as far as it applied to offenders who did not constitute a danger to children, and applied to

parks where children were unlikely to be present (Canada AG v. Bedford, 2013, par. 101). Another example of overbreadth is in *R. v. Demers* (2004) which found that provisions under the criminal code which required persons accused yet deemed unfit to stand trial to attend repeated review board hearings was overbroad. This was because the objective of the law, for ongoing treatment and assessments of individuals to become fit for an eventual trial, did not apply to individuals who would never regain capacity and who present no significant threat to public safety (Canada AG v. Bedford, 2013, par. 102). For more details on *R. v. Demers*, please refer to s. 1.3 of Chapter 1 of this work.

A deprivation of a right is grossly disproportionate where there is a rational connection to the purpose but has effects which significantly outweigh the purpose of the provision (Department of Justice, 2019, web; Canada AG v. Bedford, 2013, par. 103). In *R. v. Marmo-Levine* (2003), the Supreme Court of Canada found that a prohibition on possession of marijuana was not grossly disproportionate to its objective, as the effects on accused persons, including the potential of imprisonment, fell within the range where the Constitution permits legislative action (Canada AG v. Bedford, 2013, par. 103). The Minister of Health's decision not to extend a safe injection site's exemption from drug possession laws was found to be grossly disproportionate by the Supreme Court in *Canada (Attorney General) v. PHS Community Services Society* (2011) as the effect of denying health services and increasing the risk of death and disease among injection drug users was grossly disproportionate to the law's objectives of public health and safety (Canada AG v. Bedford, 2013, 104).

Where a provision or government action is not in accordance with the principles of fundamental justice, it unjustifiably limits rights under s. 7 of the Charter (Department of Justice, 2021, web). Further, analysis of the principles of fundamental justice is qualitative; that is, an unjustifiable limit on the rights of one person is sufficient to establish a violation of s. 7 (Department of Justice, 2021, web). In common-law precedent, s. 7 has been interpreted solely in terms of negative rights (concerned with non-interference), and does not yet impose positive obligations on the state to ensure enjoyment of life, liberty, and security of the person (Department of Justice, 2021, web). This work will now analyze a potential mature minor challenge to the law based on a violation to s. 7 rights to life, liberty, and security of the person. If the law does violate s. 7, the analysis will consider whether it is in accordance with the principles of fundamental justice.

4.2.2 Analysis: Could Bill C14 Infringe on a Child's s.7 Charter Rights?

This section considers a potential challenge to s. 241.2(1)(b) which requires that persons eligible for MAiD are at least 18 years of age and capable of making decisions with respect to their health. In her paper arguing that eligibility for MAiD should be in accordance with medical-decisional capacity rather than by age, Constance MacIntosh compares the s. 7 analysis of *Carter v. Canada* (2015) and *AC v. Manitoba* (2009). She observes that in each case, the SCC's ruling hinged on whether the law recognized that "vulnerability may not, in fact, be present in the circumstances, or alternatively that vulnerability does not necessarily undermine autonomous decisional capacity" (MacIntosh, 2016, p S21). In analyzing rights to life, liberty, and security of the person, and Principles of Fundamental Justice in both decisions, MacIntosh concludes that it is likely that a provision that completely excludes mature minors from MAiD without regard to their actual circumstances will impair their s. 7 rights (MacIntosh, 2016, p S22).

As was discussed previously in Chapter 1, ss. 14 and 241(b) violated the right to life by having the effect of forcing some individuals to take their own lives prematurely for fear that they may be incapable of doing so when their suffering becomes intolerable (*Carter v. Canada*, 2015, par. 57–58). Although the right to life was not discussed in *AC v. Manitoba* (2009), MacIntosh finds that the reasoning used in *Carter v. Canada* (2015) is, on its face, compelling in the case of mature minors (MacIntosh, 2016, pp S21–S22). According to MacIntosh, the possibility that 16-year-olds could choose to end their life prematurely rather than face living with an intolerable medical condition where they are incapable of ending their lives is completely conceivable (MacIntosh, 2016, p S22).

Further, both decisions invoke considerations of individual autonomy and dignity in defending rights to liberty and security of the person. In both *Carter* and *Truchon*, a prohibition on MAiD was found to violate liberty interests by interfering with individuals' ability to make fundamental personal decisions about their bodily integrity and medical care. Meanwhile, security of the person was violated, as the prohibition interfered with bodily integrity by forcing individuals to endure intolerable suffering (MacIntosh, 2016, p S22). A similar line of reasoning was employed in *AC v. Manitoba* (2009), where the Supreme Court of Canada ruled that minors' interests in liberty and security of the person were implicated by orders imposing treatment against the wishes of a minor, as they denied minors the ability to determine their own medical treatment (MacIntosh, 2016, p S22; *AC v. Manitoba*, 2009, par. 102). In fact, summative comments on autonomy in the *Carter* decision supported the Supreme Court of Canada's conclusion on the right to choose MAiD using reasoning in

AC v. Manitoba (2009). In particular, the Supreme Court of Canada invokes AC to claim that the principle that competent individuals are and should be free to make decisions about bodily integrity, which entitles adults to direct the course of their own medical care through informed consent, has tenacious relevance in our legal system (MacIntosh, 2016, p S22).

If an age restriction on eligibility for MAiD violates s. 7, it may still be saved by being in line with fundamental principle of justice. This stage of the mature minor's s. 7 challenge considers whether the law's exclusion of minors (a vulnerable group to whom we owe a duty of beneficence) from accessing MAiD, aligns and has proportionate effects to its objective of preventing vulnerable persons from being induced to commit suicide in a time of weakness. Analyzing whether these s. 7 infringements would be consistent with the principles of fundamental justice, MacIntosh notes that the court's reasoning in *AC v. Manitoba* (2009), paired with reasoning in *Carter v. Canada* (2015), "seems to support extending the regime which operationalizes the declaration in the Carter decision to mature minors."

The exclusion of mature minors from access to MAiD could be construed as a problem of overbreadth. In *Carter* (2015) the Supreme Court of Canada found a prohibition on MAiD was overbroad by catching some individuals outside the class of persons the law was meant to protect. The legal framework under Bill C-14 likewise overreaches its objective of protecting vulnerable minors based on incapacity to include capable minors "who can exercise an autonomous and informed choice" (MacIntosh, 2016, S23). As a result, the law treats capable minors who are able to consent to MAiD as incapable and lacking capacity (MacIntosh, 2016, S23).

Moreover, the provision could be arbitrary. MacIntosh applies arbitrariness according to a different framing of the issue by questioning the assumption inherent to the provision that a mature minor can never have the capacity to make a medical treatment decision that an adult has the capacity to make (MacIntosh, 2016, S23). Such a rigid distinction between adults and minors contradicts the reasoning which shapes Charter-compliant approaches to mature minors and medical-decisional capacity. In *Carter v. Canada* (2015), the SCC found that a prohibition on MAiD was not arbitrary because such a prohibition is rationally connected to its purpose of protecting vulnerable persons in a time of weakness (MacIntosh, 2016, p S23). *AC v. Manitoba* also identifies that the law's purpose lies in protecting the vulnerable, recognizing that there is an inherent vulnerability to childhood, which is presumed to gradually dissipate as one develops maturity. However, in the decision the SCC distinguishes between a "rigid statutory distinction," and a more flexible regime (MacIntosh, 2016, p

S23). A rigid age-based distinction was found to be arbitrary by completely ignoring children’s decision-making capabilities, failing to reflect the realities of childhood and child development, and creating an absolute bar to respecting children’s treatment wishes (MacIntosh, 2016, p S23–S25). Meanwhile, a more flexible regime allows for a case-by-case assessment of the facts and recognizes the possibility that a child may be found to have mature decisional capacity (MacIntosh, 2016, p S24). Interestingly, while it is not considered a principle of fundamental justice,³¹ the “best interests of the child” (Government of Canada, 2019, web) is invoked by *AC v. Manitoba* to strike an appropriate balance between protecting the vulnerable and enabling mature minor rights to participate meaningfully in decisions relating to their own medical treatment (2009, par. 4, 19, 82–88).

Lastly, excluding mature minors from eligibility for MAiD could also be considered grossly disproportionate. In *Carter* (2012) the trial judge found that an absolute prohibition is grossly disproportionate based on its severe negative impact on life, liberty, and security of the person (par. 1378). The Supreme Court agreed with the trial judge’s claim of the severe effects of the prohibition based on the unnecessary suffering, limits to autonomy, and the risk of shortening life. Yet the Supreme Court also recognized the high importance of protecting the vulnerable, and did not reach a conclusion on whether the law was grossly disproportionate. Thus, while there are some grounds to justify a finding that restricting minors from eligibility is grossly disproportionate, it is not clear whether the effects of the provision severely outweigh its object.

Thus, it is likely that a violation of mature minor s. 7 rights to life, liberty, and security of the person would not be in accordance with the principles of fundamental justice. Depending upon the framing of the issue (protecting the vulnerable vs. capability of minors), excluding mature minors from access to MAiD could be understood as an issue of overbreadth or an issue of arbitrariness. While a plausible argument could be made that the provision is grossly disproportionate, the high

³¹ Jurisprudence on s. 7 has established that a “principle of fundamental justice” must fulfill three criteria: (1) it must be a legal principle; (2) there must be sufficient consensus that the principle is “vital or fundamental to our societal notion of justice”; and (3) the principle must be capable of being identified with precision and applied in a way yielding predictable results (*Canadian Foundation for Children, Youth and the Law v. Canada*, 2004, par. 8). While “the best interests of the child” is an established legal principle in international and domestic law, thus meeting (1), it remains a primary consideration among many rather than the prevailing consideration (*Canadian Foundation for Children, Youth and the Law v. Canada*, 2004, par. 9–10). Therefore the “best interests of the child” standard fails to meet either (2), as it is not vital/fundamental to our societal notion of justice, or (3), as its application is highly contextual and subject to dispute (*Canadian Foundation for Children, Youth and the Law v. Canada*, 2004, par. 10–11).

importance of protecting the vulnerable may be invoked to defend the notion that the law is not grossly disproportionate.

4.3 Section 15 - Does s. 241.2(b) Violate Rights to Equality?

While it is plausible that a challenge to the law on the basis of violations of mature minors' section 7 rights to life, liberty, and security of the person would be successful, another intuitive critique of the statutory regime in the mature minor context is that it discriminates on the basis of age. The question of age discrimination was debated in the Belgian context, as the most common argument to extend their euthanasia law to mature minors was that it would dispose of an unjust distinction between emancipated minors (who could obtain euthanasia) and non-emancipated but otherwise competent minors (who were ineligible for euthanasia) (Raus, 2016, p 308). Proponents of extending the law argued that this distinction between emancipated and non-emancipated minors was unfair, as competent non-emancipated minors are equally psychologically mature and experience comparable degrees of acute suffering (Raus, 2016, p 308).

In Canada, considerations of equality have featured prominently in case precedent on the issue of MAiD. Chapter 1 reviewed arguments that a prohibition of MAiD, as well as the eligibility requirement that a natural death become reasonably foreseeable, violate s.15 equality rights, made in previous Charter challenges. In *Rodriguez v. BC* (1993) and later in *Carter v. Canada* (2015) applicants made the argument that s. 241 of the Criminal Code creates an inequality by depriving physically disabled persons of the right to choose suicide (*Rodriguez v. BC*, 1993, p 524i; *Carter v. Canada*, 2015, par. 29). Although this argument did not yield a successful challenge in either case,³² s. 15 was later successfully challenged using a similar line of argument in *Truchon c. Procureur général* (2019). Applicants argued that the criterion of a reasonably foreseeable natural death did not sufficiently consider individual circumstances, and therefore propagates perceptions that it is unlikely that persons with disability can express valid consent to MAiD (*Truchon c. Procureur général du Canada*, 2019, par. 678, 680–681).

³² In *Rodriguez v. BC* (1993), the majority chose not to deliberate upon whether there was a s. 15 violation but rather to assume there is one, arguing that any infringement of s. 15 is clearly justified under s. 1 of the Charter (*Rodriguez v. BC* 1993, p 522i–j). Meanwhile in *Carter v. Canada* (2015), as s. 7 was found to be violated in *Carter*, s. 15 equality rights and the relevant moral issues were not contemplated as they were in *Rodriguez* (*Carter v. Canada* 2015, par. 93).

4.3.1 *Truchon v. Procureur Général* (2019)

Truchon v. Procureur général du Canada (2019) challenged the constitutional validity of the provision that a person's natural death must be reasonably foreseeable (*Truchon c. Procureur général du Canada*, 2019, par. 3–5). Along with the challenge that the provisions engage s. 7 rights to life, liberty, and security of the person, the applicants argued that the provisions engaged s. 15 of the Charter (*Truchon c. Procureur général du Canada*, 2019, par. 683, 708). The requirement that a natural death be reasonably foreseeable was found to create a distinction based on physical disability as an enumerated ground in two respects. One distinction is on the basis of the foreseeability of natural death, the other on the basis of the ability to end one's life unassisted (*Truchon c. Procureur général du Canada*, 2019, par. 652, 665). Moreover in the context of paternalistic stereotypes/prejudices about the vulnerability of disabled persons, such distinctions based on physical disability were found to perpetuate disadvantage, as the provisions did not “consider the applicants’ personal circumstances, characteristics, and actual needs” in order to respect their value as human beings compared to those recognized with the right to access MAiD (*Truchon c. Procureur général du Canada*, 2019, par. 673–674). The court's conclusions on whether the s. 7 violations are saved by s. 1 also applied to the s. 15 violations of both provisions, which likewise were not saved by s. 1 (*Truchon c. Procureur général du Canada*, 2019, par. 685, 731).

The *Truchon* decision and the resulting changes in eligibility criteria outlined in Bill C-7 introduce new insights into conflicting values of respecting autonomy and protecting the vulnerable, which underlie the *Carter* decision along with issues for independent review, including the mature minor issue. The court acknowledged two undisputed stereotypes and prejudices facing physically disabled person involving problematic responses from society and the state (*Truchon c. Procureur général du Canada*, 2019, par. 670–672). One is the perception that persons with disability are vulnerable due to incapability of making the “right decisions” concerning their body and life and requiring state protection from their “poor choices” (*Truchon c. Procureur général du Canada*, 2019, par. 672). Those who challenge this perception argue there is a risk of persons with a disability being inappropriately blocked from accessing MAiD in a way that violates autonomy. The other stereotype is the view that physical disability constitutes a loss of dignity and a diminished quality of life, which inform a desire to die (*Truchon c. Procureur général du Canada*, 2019, par. 672). Those who challenge this perception argue that there is a risk to the welfare of persons with a disability who may too easily qualify for MAiD under the legal framework. Both stereotypes pose risks to the disabled by misvaluing their lives, experiences, and capabilities in different ways.

The attorney general argued on behalf of the government that removing the criterion that a patient's natural death must be reasonably foreseeable would send a negative message that would "reinforce and entrench stereotypes about the quality of life and value of the lives of the disabled" (Truchon c. Procureur général du Canada, 2019, par. 668). Responding to this argument, Justice Baudouin clarified that in safeguarding the vulnerable, there ought to be sufficient consideration of individual needs, characteristics, and circumstances. Justice Baudouin determined that, in the context of these prejudices and stereotypes about the vulnerability of disabled persons, the requirement of a reasonably foreseeable natural death is grounded in paternalism (Truchon c. Procureur général du Canada, 2019, par. 680). As a protective policy adopted regardless of an individual's personal situation, the provision requiring a reasonably foreseeable natural death propagates the perception that the autonomy of persons with a disability is necessarily compromised by their vulnerability, based on the view that it is unlikely that persons with disability can express valid consent to MAiD (Truchon c. Procureur général du Canada, 2019, par. 678, 680–681). In particular, there is concern that the desire to die is motivated by self-stigmatism, unsatisfied needs, diminished capacity for resilience, depressive symptoms, or subtle social pressures (Truchon c. Procureur général du Canada, 2019, par. 680).

What is lost in these categorizations of vulnerability according to the presence of a disability and proximity to death are an individual's personal circumstances and characteristics, which are central considerations in respecting one's value as a human being (Truchon c. Procureur général du Canada, 2019, par. 673). Where evidence exists of capability to exercise fundamental choices concerning life and death, one is deprived of choices essential to one's dignity as a human being based on a perception without adequate exploration of personal circumstances (Truchon c. Procureur général du Canada, 2019, par. 681). This judgment, which clarifies equality and protecting the vulnerable, likewise raises questions of equality when it comes to how the capability and perceived vulnerability of mature minors may also be shaped by prejudice and stereotyping. These questions will be discussed further in s. 4.4 of this chapter.

4.3.2 s.15(1),(2) Equality Rights under the Charter

The equality rights in section 15 are invoked in the first subsection of the provision, 15(1). Section 15(1) states that "every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age or mental or physical

disability” (Canadian Charter, 1982, s 15). Non-citizenship, marital status, sexual orientation, and Aboriginality-residence, while not formally listed under s. 15 of the Charter, are analogous grounds for s. 15 protection.³³ Meanwhile the second subsection of s. 15 qualifies the equality rights of s. 15(1), stating that “subsection (1) does not preclude any law, program or activity that has as its object the amelioration of conditions of disadvantaged individuals or groups including those that are disadvantaged because of race, national or ethnic origin, colour, religion, sex, age or mental or physical disability” (Canadian Charter, 1982, s. 15). This provision enables the government to combat discrimination through affirmative measures.

Commenting on the purpose of s. 15 nearly 20 years after their first ruling on an equality issue in 1989, the SCC claim in *R. v. Kapp* that equality rights under the Charter are motivated by substantive equality rather than formal equality (2008, par. 15). Formal equality entails a “like treatment” model, requiring identical treatment to achieve equality (*R. v. Kapp*, 2008, par. 15). Recognizing that formal equality may actually produce inequality through the use of sterile similarity tests focused on treating “likes” alike, the SCC characterize s. 15 with substantive equality (*R. v. Kapp*, 2008, par. 15). Substantive equality is an equality of benefit and protection, where the main consideration is the impact of the law on the “human dignity” of members of the claimant group (*R. v. Kapp*, 2008, par. 15, 19). Substantive equality strives for a society where irrelevant personal differences do not have more burdensome or less beneficial impacts on particular individuals or groups (*R. v. Kapp*, 2008, par. 15).

Subsections (1) and (2) interact to promote the substantive equality underlying s. 15 (*R. v. Kapp*, 2008, par. 16). Section 15(1) targets discriminatory distinctions identified by the enumerated and analogous grounds listed (*R. v. Kapp*, 2008, par. 16). The focus of s. 15(1) is on preventing governments from making distinctions that perpetuate disadvantage or prejudice, or impose disadvantage on the basis of stereotyping (*R. v. Kapp*, 2008, par. 37). Section 15(2) meanwhile gives governments the right to develop and implement programs aimed at helping disadvantaged groups improve their situation without fear of challenge under s. 15(1) (*R. v. Kapp*, 2008, par. 28). Such

³³ Non-citizenship was established through *Andrews v. Law Society of British Columbia*, *Lavoie v. Canada*; marital status through *Miron v. Trudel*, *Nova Scotia (Attorney General) v. Walsh*, *Quebec v. A.*; sexual orientation through *Egan v. Canada*, *Vriend v. Alberta*, *M. v. H*, *Little Sisters Book and Art Emporium v. Canada (Minister of Justice)*; and Aboriginality-residence as it pertains to a member of an Indian Band living off the reserve through *Corbiere v. Canada (Minister of Indian and Northern Affairs)* (Department of Justice, 2021, web).

programs are designed to ameliorate the disadvantage of one group, and inevitably exclude individuals from other groups (*R. v. Kapp*, 2008, par. 28). This follows from the SCC's position that not every distinction is discriminatory (*R. v. Kapp*, 2008, par. 28), and that different treatment for the purpose of achieving equity expresses equality rather than undermining it (*R. v. Kapp*, 2008, par. 37).

Supreme Court's decision in *R. vs. Kapp* (2008) that the Aboriginal Fisheries Strategy program was not discriminatory exemplifies amelioration under s. 15(2) of the Charter. The Aboriginal Fisheries Strategy was a program to enhance Aboriginal involvement in the commercial fishery, which included the issuance of a communal fishing licence to fishers designated by three Aboriginal bands to fish for salmon in the mouth of the Fraser River for a period of 24 hours and to sell their catch (*R. v. Kapp*, 2008, par. 7). The appellants, mainly non-Aboriginal commercial fishers, who were excluded from the fishery during this 24-hour period, argued that the communal fishing licence discriminated against them on the basis of race (*R. v. Kapp*, 2008, par. 9). The government successfully defended the program on the basis of a credible ameliorative purpose, including objectives of "negotiating solutions to Aboriginal fishing rights claims, providing economic opportunities to native bands and supporting their progress towards self-sufficiency" (*R. v. Kapp*, 2008, par. 58, 61).

4.3.3 Two-Part Test in Applying s. 15 to Charter Challenges

In addition to commenting on the purpose of s. 15 of the Charter in *R. v. Kapp* (2008), the SCC developed a two-part test to demonstrate discrimination under s. 15(1) of the Charter. The first part of the test creates a burden of proof on the claimant to show that the law creates a distinction based on an enumerated or analogous ground (*R. v. Kapp*, 2008, par. 17). Enumerated grounds are directly referenced within s. 15(1) of the Charter, including race, national or ethnic origin, colour, religion, sex, age, and mental or physical disability (Department of Justice, 2021, web). Analogous grounds are not directly mentioned in s. 15(1) of the Charter, but are determined by the courts to be grounds for s. 15 protections. To date, the SCC have determined non-citizenship, marital status, sexual orientation, and Aboriginality-residence as analogous grounds for discrimination (Department of Justice, 2021, web).

The second part asks whether such a distinction creates a disadvantage by perpetuating prejudice or stereotyping (*R. v. Kapp*, 2008, par. 17). The effects created by a distinction are highly significant to the second part of the test. The SCC specifically considered whether a distinction created effects that impose burdens, obligations, or disadvantages on an individual or group that are not imposed upon

others, or withhold access to opportunities, benefits, or advantages available to others (*R. v. Kapp*, 2008, par. 18). The complainant must show not only that the law creates a differential impact on them, but that the legislative impact of the law is discriminatory (*R. v. Kapp*, 2008, par. 28).

Where the law fails the two-part test under s. 15(1), it falls to the government to justify the distinction under s. 15(2) of the Charter in terms of an additional two-part test developed by the SCC in *R. v. Kapp* (2008, par. 40). The first part of the test requires the government to demonstrate that the law has an ameliorative or remedial purpose (*R. v. Kapp*, 2008, par. 41). The second part of the test requires that the law target a disadvantaged group identified by the enumerated or analogous grounds under s. 15(1) (*R. v. Kapp*, 2008, par. 41). Rather than focusing on the effects of the distinction, this two-part test gives primary consideration to the legislative goal of the program (*R. v. Kapp*, 2008, par. 44). Yet the government must also prove that the distinction is a rational means to reach its ameliorative goal (*R. v. Kapp*, 2008, par. 49). This involves demonstrating a correlation between the law and the disadvantage suffered by the target group (*R. v. Kapp*, 2008, par. 49).

In practice, the two-part test is not conducted in the order described above. The SCC state in their analysis of the tests under s. 15 that if the government can demonstrate that a program meets the criteria of s. 15(2), it may be unnecessary to conduct a s. 15(1) analysis (*R. v. Kapp*, 2008, par. 37). This is because s. 15(2) interprets s. 15(1) such that an ameliorative program aimed at combatting disadvantage cannot be considered discrimination breaching s. 15 (*R. v. Kapp*, 2008, par. 39). Taking this into account, analysis of s. 15 starts with the claimant demonstrating that the challenged law, program, or activity fails the first part of the test under s. 15(1) by making a distinction on an enumerated or analogous ground (*R. v. Kapp*, 2008, par. 40). It is then open to the government to show under s. 15(2) that the challenged law, program, or activity is ameliorative and thus constitutional (*R. v. Kapp*, 2008, par. 40). If the government fails both parts of the test under s. 15(2), the program must then receive full scrutiny to determine whether its impact is discriminatory according to the second part of the test under s. 15 (1) (*R. v. Kapp*, 2008, par. 40).

In the following section, this two-part test to apply s. 15 to Charter challenges will pertain to the issue of mature minor eligibility for MAiD. The analysis will first consider whether age imposes disadvantage as an enumerated ground under s. 15(1) of the Charter. A particular challenge lies in reconciling disadvantage imposed by an age distinction with the argument that age distinctions are a common and necessary way of ordering society. The analysis will then consider whether excluding

mature minors on the basis of their age can be justified by an ameliorative purpose, contemplating whether restricting minors from access to MAiD is beneficial or an imposed limitation.

4.4 Mature Minor Exclusion as a Case of Age Discrimination

Is the law's restriction of mature minor eligibility for MAiD a case of age discrimination? Where equality considerations of persons with a disability were central to previous s. 15 challenges to the Criminal Code, a s. 15 challenge in the context of a mature minor would likely argue that capacity, rather than age, ought to determine eligibility for MAiD. Analysis of potential s. 15 challenges draws heavily from the SCC judgment in *AC v. Manitoba* (2009), where a s. 15 challenge was argued in the context of a mature minor's refusal of life-sustaining treatment. In their judgment, the SCC gave valuable analysis of s. 15 in the context of age and equality, before concluding that there was no s. 15 violation – "because capacity, not age, was the true determinant of whether the child would have the right to make their own treatment decision" (MacIntosh, 2016, S23).

4.4.1 Safeguarding Should Be Calibrated in Terms of Maturity Rather than Age

The premise that safeguarding the vulnerable ought to take into consideration the needs, circumstances, and characteristics of individuals is applicable to the question of whether the provision that a person must be over 18 to be eligible for MAiD is discriminatory on the basis of age (s. 241.2(1)(b) of the Criminal Code). With respect to mature minor decisions, this notion of sufficient consideration of individuals is expressed in terms of the argument that mature minor capacity should be understood in terms of maturity rather than age. In *AC v. Manitoba*, the SCC heard a Charter challenge surrounding the constitutionality of s. 25(8) and s. 25(9) of the Child and Family Services Act (2009, par. 25). AC argued that these provisions violated s. 15 because they discriminated against her on the basis of age (*AC v. Manitoba*, 2009, par. 27). In her argument, discrimination hinges on whether adolescents under 16 are able to rebut the presumption of their incompetence. Rather than challenging the constitutionality of the use of an age cut-off at 16, AC's argument was that the unconstitutionality of the provisions lies in "depriving those under 16 of an opportunity to prove that they too have sufficient maturity to direct the course of their medical treatment" (*AC v. Manitoba*, 2009, par. 25). She submitted that in common law, mature minors have a similar capacity to adults in deciding their own medical care (*AC v. Manitoba*, 2009, par. 25). Still, AC concludes in her argument that if s. 25(8) and s. 25(9) permitted her to demonstrate that she had sufficient decisional maturity, she would agree there is no discrimination in the law (*AC v. Manitoba*, 2009, par. 27).

With regard to the Child and Family Services Act in particular, the SCC agreed with AC in their judgment that there is no constitutional justification for a provision that ignores the decision-making capacity of children under 16 (*AC v. Manitoba*, 2009, par. 29). In their judgment, the Manitoba court

of appeal had found no breach of s. 15 equality rights, as the legislation attempts to be responsive to characteristics of children as a group, including children's dependency and reduced maturity (AC v. Manitoba, 2009, par. 19). The SCC diverged from this opinion, finding that the constitutionality of the provision lies in upholding the child's "best interests" (AC v. Manitoba, 2009, par. 19).

The SCC interprets "best interests" to require sufficient consideration of adolescent maturity on a case-by-case basis for any medical treatment context. "Best interests" is a guiding standard used by the courts to act on behalf of the vulnerable (AC v. Manitoba, 2009, par. 81). Competent adults, in contrast, are entitled to independently assess and determine their own best interests, as they are assumed to be "the best arbiter[s] of [their] own moral destiny" (AC v. Manitoba, 2009, par. 81). One reason a best-interests standard is pivotal to whether legislation discriminates based on age is that an approach particular to each patient more accurately reflects child development than rigid age cut-offs. The application of the best-interests standard to infants and very young children is generally uncontroversial (AC v. Manitoba, 2009, par. 82). Yet there are added complexities in the case of mature adolescents, who have strong claims to autonomy but are also subject to protective duties on the part of the state (AC v. Manitoba, 2009, par. 82).

The SCC acknowledge the inherent imprecision of childhood and adolescent development, and that standards of maturity are necessarily imprecise standards (AC v. Manitoba, 2009, par. 4). Rather than there being a clear "eureka" moment for its discovery by the judiciary, adolescent maturity depends on the court's assessment of their circumstances and ability to exercise independent judgment, and the nature and consequences of the decision at issue (AC v. Manitoba, 2009, par. 4). Further, determining maturity on a case-by-case basis responds to complex tensions between autonomy and child protection (AC v. Manitoba, 2009, par. 83). In determining best interests, the SCC assert that a thorough assessment of maturity is necessary to respect an adolescent's evolving right to autonomous medical decision-making (AC v. Manitoba, 2009, par. 4). In fact, through respect for a mature adolescent's capacity for autonomous judgment to be within their best interests, principles of welfare and autonomy may narrow considerably and often collapse altogether (AC v. Manitoba, 2009, 84).

Reflecting on these factors which lend to the complexity of adolescent medical decision-making, the SCC claim that "the more a court is satisfied that a child is capable of making a mature, independent decision on his or her own behalf, the greater the weight that will be given to his or her views when a court is exercising its discretion under s. 25(8) [of the Manitoba Child and Family Services Act]" AC v. Manitoba, 2009, par. 87). Further they assert that "it is, by definition, in a

child's best interests to respect and promote his or her autonomy to the extent that his or her maturity dictates" (AC v. Manitoba, 2009, par. 88). Thus, where the courts are extremely convinced of the child's maturity, the child's wishes will become the controlling factor, collapsing principles of welfare and autonomy altogether (AC v. Manitoba, 2009, par. 87). Further, the SCC ruled that "in the context of medical treatment, young people under 16 should be permitted to attempt to demonstrate that their views about a particular medical treatment decision reflect a sufficient degree of independence of thought and maturity" (AC v. Manitoba, 2009, par. 87).

The SCC observed that calibrating the role of self-determination in determining a child's best interest according to their maturity is consistent with the United Nations Convention on the Rights of the Child (AC v. Manitoba, 2009, par. 93). They also reference the Council of Europe's Convention for the Protection of Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine. Article 6(2) states: "The opinion of the minor shall be taken into consideration as an increasingly determining factor in proportion to his or her age and degree of maturity" (Convention on Human Rights and Biomedicine).

4.4.2 Age Distinctions and Arbitrary Disadvantage

Applying the two-part test to the issue of mature minor eligibility for MAiD, a s. 15 analysis of the mature minor issue meets the first premise of the two-part test under s. 15(1): age is an enumerated ground under the Charter, and Bill C-14 creates a distinction on the basis of age. Yet in determining whether an age distinction in this case is discriminatory, a challenge lies in reconciling disadvantage on the basis of age with the premise that age distinctions are acceptable as a common and necessary way of ordering society. A key component of this balance is determined according to whether a given age distinction is arbitrary, and therefore must be scrutinized on whether it perpetuates disadvantage. In *AC v. Manitoba* (2009), such reasoning was prominent in the Manitoba Court of Appeal's judgment (2007) that a threshold age of 16 was not arbitrary according to the principles of fundamental justice, claiming that "a fixed age has been chosen as the dividing line for other purposes regarding children and fundamental life choices" (AC v. Manitoba, 2009, par. 17). According to the Court of Appeal, regardless of whether one is a mature minor, children cannot determine whether to attend school, choose where to live when their parents' divorce, or decide to marry (AC v. Manitoba, 2009, par. 17). Further, the SCC has upheld age distinctions that determine when a person can vote, drive, consent to sexual intercourse, and sell property (AC v. Manitoba, 2009, par. 110).

The attorney general of Manitoba exemplified this line of argument, conceding that the Child and Family Services Act imposes differential treatment on the basis of age, but denying that the distinction is discriminatory (*AC v. Manitoba*, 2009, par. 229). In making this claim, the attorney general relied on a remark from the Chief Justice in *Gosselin v. Quebec (AG)*, distinguishing age, from other enumerated grounds for discrimination:

[U]nlike race, religion, or gender, age is not strongly associated with discrimination and arbitrary denial of privilege. This does not mean that examples of age discrimination do not exist. But age-based distinctions are a common and necessary way of ordering our society. (2002, par. 31)

This reasoning relates to the “argument from consistency,” which will be discussed further in Chapter 6 of this dissertation.

In his dissenting opinion in the *AC v. Manitoba* (2009) decision, Justice Binnie challenges the perception that age distinctions are non-discriminatory. Justice Binnie declares this claim to be true in certain contexts but inaccurate in others (*AC v. Manitoba*, 2009, par. 31). Specifically, where age is employed to indicate ability, there is a risk that age distinctions are an arbitrary³⁴ use of regulation. Justice Binnie quotes Peter Hogg in arguing that laws where age is used as a qualification for pursuits requiring skill or judgment impose disabilities on young people based on inaccurate stereotyping (*AC v. Manitoba*, 2009, par. 31). Further, because individuals mature at different rates, such age distinctions could be eliminated in favour of individual evaluations of capacity (*AC v. Manitoba*, 2009, par. 31).

Indeed, AC argued that being irrebuttably presumed incompetent is both inaccurate and harmful. Comparing her position to that of mature minors who can rebut their presumption of incapability, AC argued that the rigid age distinctions significantly intrudes upon her life through forced medical treatment (*AC v. Manitoba*, 2009, par. 230). Specifically, using age 16 to distinguish between capability and incapability does not correspond with the reality of mature minors (*AC v. Manitoba*, 2009, par. 230).

This argument made reference to a report by the Manitoba Law Reform Commission, which rejected the option of regulating mature minor decision making with a “fixed age” cut-off. Justifying

³⁴ Here, ‘arbitrary’ is meant in the literal sense, rather than in terms of the s. 7 principle of fundamental justice.

their decision, the Commission identifies challenges in selecting a particular age to make the cut-off, as too much depends on the specific medical treatment (Manitoba Law Reform Commission, 2005, p 33). For instance, where very young minors could consent to trivial first aid, an older age may be necessary to select from a range of treatment options in the case of a serious illness (Manitoba Law Reform Commission, 2005, p 33). In addition to variety in the seriousness and significance of medical procedures, individualized capacity assessments incorporate considerations of different paces of child development, differences in family relationships, and varying socio-economic circumstances of children (Manitoba Law Reform Commission, 2005, p 33).

A middle ground between accepting age distinctions as a “common and necessary way to order society” and avoiding inaccurate stereotyping on the basis of age is the use of age distinctions to presume competence or incompetence of a minor. In the majority judgment for the SCC, Justice Abella accepted that the use of age distinctions is often arbitrary in a literal sense. Despite such arbitrariness, the SCC asserted that age distinctions can be justifiable where the chosen age is reasonably related to the legislative goal of the distinction (*AC v. Manitoba*, 2009, par. 110). While the examples of marriage, voting, driving, consenting to sexual intercourse, and selling property are outside the scope of the judgement, in the context of medical decision-making Justice Abella determined that the use of age distinctions is acceptable as an indicator to shift presumptions of capacity (*AC v. Manitoba*, 2009, par. 111). Individuals below the age of consent are presumed to lack capacity unless proven otherwise, and those above the age of consent are presumed to be capable unless proven otherwise (*AC v. Manitoba*, 2009, par. 111). Interpreting s. 25(8) of the Child and Family Services Act such that minors can rebut presumptions of incompetence, the SCC argued that their ability to make treatment decisions should be calibrated in accordance with maturity rather than age.

Applying this reasoning to the case of a potential s. 15 challenge to s. 241(b) of the Criminal Code, the requirement that a patient must be over 18 years of age to be eligible for MAiD risks being found to be an arbitrary use of an age distinction. In particular, by implementing a firm age distinction such that minors cannot rebut the presumption of their incompetence, the eligibility requirements risk imposing disabilities on minors based on inaccurate and harmful stereotyping about the relationship between their age and their capacity to consent to MAiD. Such stereotypes ignore factors specific to the individual, including considerations of the individual’s experiences of suffering, the stage of their

illness, disease, or disability, their particular stage of child development, their family relationships, and their socio-economic circumstances.

4.4.3 Are the Purpose or Effects of s. 241.2(b) of Bill C-14 Ameliorative?

If the law disadvantages a group based on enumerated grounds under s. 15(1) of the Charter, it may still be constitutional if the law has an ameliorative purpose under s. 15(2). Defenders of an age restriction on eligibility for MAiD may argue that the law has an ameliorative purpose, by protecting mature minors as a uniquely vulnerable group from being induced to commit suicide in a time of weakness. In particular, the law benefits mature minors by preventing them from making decisions for which they are not sufficiently autonomous. Section 15(2) of the Charter protects programs which target disadvantaged groups along the enumerated or analogous grounds of s. 15(1) if they aim to ameliorate their condition. If the goal of protecting the vulnerable is ameliorative, eligibility provisions for MAiD could be justified as non-discriminatory. Where a provision does not meet the requirements of an ameliorative purpose, it may be possible to argue against a finding of discrimination based on its ameliorative effects (Department of Justice, 2019, web).

Much of the analysis in this chapter on the questions of mature minor eligibility for MAiD has relied upon precedent cases on the issues of MAiD through *Carter* (2015) and *Truchon* (2018), and the issue of mature minor capacity through *AC* (2009). Yet none of these cases provide clear guidance on amelioration under s. 15 of the Charter. In *Carter v. Canada* (2015), the SCC gave no s. 15 analysis, and while the Quebec Superior Court provided s. 15 analysis in *Truchon c. Procureur général du Canada* (2019), the issue of whether the purpose of s. 241(b) was ameliorative was not considered. The question was considered in *Carter v. Canada* (2012), where the trial judge gave a narrow interpretation of s. 15(2) such that an ameliorative purpose or effect is only relevant where the group excluded from an ameliorative law is relatively more advantaged (*Carter v. Canada*, 2012, par. 1139–1140). This would restrict the applicability of s. 15(2) to cases similar to *R. v. Kapp*, where the appellants were mainly non-Indigenous and tended to be more economically advantaged. Determining that materially physically disabled affected by the Criminal Code are “less advantaged, in a relative sense, than other Canadians able to die without attracting attention of the Criminal Code” (*Carter v. Canada*, 2012, par. 1140), the trial judge concluded that the ameliorative purpose or effect had no application to the context of MAiD. The previous section established that mature minors are similarly less advantaged under the law that other Canadians, who are permitted to exercise their autonomy to consent to MAiD. Thus, while the Supreme Court of Canada did not consider the

question, the trial judge's analysis in *Carter* suggests that the question of amelioration under s. 15(2) is unlikely to be addressed in a future challenge by a mature minor.

Yet, protecting children as vulnerable persons has been interpreted to constitute amelioration under s. 15(2) of the Charter. Finding its purpose was to benefit of the special needs of minors, the Manitoba Court of Queen's Bench used s. 15(2) to justify a Winnipeg bylaw restricting youth under the age of 16 from operating an amusement device without the consent of a guardian or a parent³⁵ in *R. v. Music Explosion Ltd.* (*R. v. Kapp*, 2008, par. 53). Interpreting restrictive legislation as ameliorative under s. 15(2), on grounds that it protects the vulnerable, is also invoked in the context of youth criminal justice. In *Re M and the Queen*, the Manitoba Court of Queen's Bench dismissed an application arguing that the definition of 'prisoner' in s. 2 of the Prisons and Reformatories Act is discriminatory because it excludes young offenders from the entitlement to earned remission (*Re M and the Queen*, 1985, p 116). Along with exclusion from earned remission, s. 28 of the Young Offenders Act outlines cumbersome procedures for early release of a young offender (*Re M and the Queen*, 1985, p 118). The Manitoba Court of Queen's Bench agreed that denying young offenders earned remission would be discriminatory if considered in isolation, but in the context of all of the provisions of the Young Offenders Act, they assert that exclusion from earned remission is "part and parcel of the complete scheme ... [of a] law ... that has as its object the amelioration of conditions of [young persons]" (*Re M and the Queen*, 1985, p 118). In other words, they argue that the provision for earned remission should not be applicable because the law overall provides different types of incarceration and lesser penalties generally for young offenders (*Re M and the Queen*, 1985, p 118).

Courts have also used s. 15(2) to uphold provisions of the Criminal Code. In *R. v. Rebic*, the petitioner of the case was being held in custody after he was found not guilty of assault and threatening to use a weapon by reason of insanity. He sought an order against being kept in strict custody, arguing that the relevant provisions of the Criminal Code at the time (s. 542(2) and s. 545) violated s. 15 of the Charter. Addressing s. 542(2) of the Criminal Code in terms of s. 15(2) of the

³⁵ The accused company was an amusement parlour enterprise and was charged under City of Winnipeg Bylaw No 4007/85, Part III, s 12 (1), which stated: "No person licensed to operate an amusement device shall permit any minor under 16 to play or operate any amusement device within his control unless such minor provides the written consent of his parent or guardian in the form attached and marked Schedule H to this bylaw." (*R. v. Music Explosion*, 1989, p 190[1]; *R. v. Music Explosion*, 1996, p 312[1]). In 1902 the province of Manitoba enacted the Municipal Act to give municipalities the power to license and regulate pool halls (*R. v. Music Explosion*, 1990, p 573b). Winnipeg Bylaw No 4007/85, Part III, s 12 (1) was a companion provision that was later enacted to prohibit persons under 18 from playing videogames (*R. v. Music Explosion*, 1990, p 573f-h; *R. v. Music Explosion*, 1996, p 312[1]).

Charter, the Supreme Court of British Columbia argued that it aims to ameliorate the conditions of individuals disadvantaged due to a mental disability (*R. v. Rebic*, 1985, par. 21). Invoking *Jones v. United States*, the Supreme Court of British Columbia interpreted that one purpose of commitment following an insanity acquittal is the protection of the individual and society from danger (*R. v. Rebic*, 1985, par. 21). Thus, they ruled that the committed acquittee is entitled to release after an indeterminate length of commitment subject to periodic review, where they have recovered their sanity or are no longer dangerous (*R. v. Rebic*, 1985, par. 14, 21).

However, the SCC distinguished protective restrictions from punishment in their analysis of amelioration. In *R. v. Kapp* (2008), the SCC determined that laws designed to restrict or punish behaviour do not qualify for s. 15(2) protection (*R. v. Kapp*, 2008, par. 54). While discrimination cannot be measured in terms of the effect of the law (as mentioned in the earlier section on s. 15 of the Charter), the SCC determined that the state's ameliorative purpose of a law should entail a plausible or predictable ameliorative effect (*R. v. Kapp*, 2008, par. 54). This reasoning is reflected in *R. v. Music Explosion Ltd.*, where the decision from the Manitoba Court of Queen's Bench was later reversed on appeal. In this later decision, the court reasoned that the legislation imposed a limitation: it neither conferred special benefits upon young people, nor had a purpose of ameliorating the conditions of youth (*R. v. Kapp*, 2008, par. 53).

If found to be relevant to a mature minor challenge to Bill C-14, restricting mature minors from access to MAiD could likewise be conceived as an imposed limitation rather than a benefit. Treating mature minors as incapable of consenting to MAiD without providing them the opportunity to prove their capacity risks unjustified paternalism, and refusing to relieve their suffering forces suffering upon them without adequate cause (*Carter v. Canada*, 2015, par. 315). Evidence gathered in *Carter v. Canada* (2012) describes unbearable pain suffered at the end of life, which cannot be alleviated despite the best possible palliative care. In addition to pain, some witnesses described other symptoms causing discomfort, agitation, and restlessness (including nausea, vomiting, and shortness of breath), and a profound sense of loss of dignity (*Carter v. Canada*, 2012, par. 190). Witnesses also reported fear and suffering from "the knowledge that they lack the ability to bring a peaceful end to their lives at a time and in a manner of their own choosing" (*Carter v. Canada*, 2015, par. 14). Where palliative sedation is used, the death process may be prolonged, in some cases taking over three days – depending on the patient's condition, the strength of their cardiorespiratory system, and their

hydration, the patient's suffering at the end of life may be experienced over a period of weeks³⁶ (Carter v. Canada, 2012, par. 258). For patients experiencing intolerable suffering, despite losing time in life, death bringing an end to suffering is conceived as a benefit rather than a harm (Carter v. Canada, 2015, par. 315).

4.4.4 Section 1 of the Charter

Under *Carter v. Canada* (2015), s. 1 analysis was framed in terms of whether a permissive regime employing safeguards (rather than a complete prohibition) could address risks to the vulnerable (Carter v. Canada, 2015, par. 117). The SSC found that the law was not minimally impairing, as a permissive regime can be established to address the risks associated with MAiD through a carefully designed and monitored system of safeguards (Carter v. Canada, 2015, par. 117). Constance MacIntosh argues that this question will likely be readdressed if a challenge is brought regarding mature minors (2016, p S26). Further, while no s. 1 analysis was given in *AC v. Manitoba* (2009) as the impugned provisions were found to violate neither s. 7 nor s. 15 of the Charter, MacIntosh makes the interesting observation that reasoning and findings in *AC v. Manitoba* (2009) were used “to illustrate that safeguards can be designed and implemented to protect those who ask for physician-assisted death and who are potentially vulnerable” (2016, p S26). In making this illustration, the SCC emphasized the validity of individual assessments of decisional capacity in the case of adolescent refusal of life-sustaining treatment (Carter v. Canada, 2015, par. 115–116). Arguably, “the court's confidence that physicians can assess adolescent decisional capacity in the context of life-and-death decisions that gave the court confidence that physicians can assess adult decisional capacity to consent to physician-assisted dying” (MacIntosh, 2016, p S26).

In his dissenting opinion,³⁷ Justice Binnie found that the impugned provisions violated section 7 and were not saved by section 1. Binnie found the care and protection of children to be a pressing and

³⁶ It is important to note that palliative sedation can include both intermittent and continuous sedation, as well as both superficial and deep sedation (Carter v. Canada, 2012, par. 42).

³⁷ In her article “The Dissenting Opinion: Voice of the Future?,” Justice L’Heureux-Dubé discussed the history and role of dissenting opinions in Canadian law. Justice L’Heureux-Dubé acknowledges that dissenting opinions should not be directly credited for future judicial decisions, and that in most cases it is the majority opinion which blazes the law’s trail (2000, pp 498, 508). Yet Justice L’Heureux-Dubé argues that as a valuable means of expressing new and alternative ideas without going so far as to cause an immediate change to the status quo, dissenting opinions can play a key role in laying the foundations for future decisions (2000, pp 504, 509). Dissenting opinions can be especially prophetic in cases where appeals raise novel constitutional law issues, or insofar as they invite dialogue about emerging social and political issues (L’Heureux-Dubé, 2000, pp 505, 508). It is in the spirit of such dialogue that this work analyzes Justice Binnie’s dissenting opinion.

substantial legislative objective of sufficient importance to justify limiting a Charter right (*AC v. Manitoba*, 2009, par. 233). Yet he found that the impugned provision was not rationally connected to this objective, as minors under 16 are denied the opportunity to demonstrate what is presumed for minors over 16 (*AC v. Manitoba*, 2009, par. 233). Further, a firm age distinction to determine capacity is not minimally impairing. Similarly to the reasoning later employed in *Carter*, Binnie refers to Manitoba's Health Care Directives Act and the Mental Health Act examples of a less restrictive regime addressing risks to the vulnerable, each of which offer a rebuttable presumption of capacity as a legislative solution (*AC v. Manitoba*, 2009, par. 234–235). Lastly, Binnie determined that the state's interest is not advanced by overriding the Charter rights of mature minors under 16, who do not lack capacity or maturity, and an irrebuttable presumption of incapacity therefore has a grossly disproportionate effect on mature minor rights (*AC v. Manitoba*, 2009, par. 237).

4.5 Conclusion

In conclusion, based on analysis of jurisprudence on capacity and vulnerability regarding end-of-life treatment decisions, this chapter has argued that a mature minor challenge to Bill C-14 would have a strong claim on the basis of violations to s. 7 and s. 15 of the Charter. The chapter considered the rulings in *Carter v. Canada* (2015) and *Carter v. Canada* (2012), *Truchon c. Procureur général du Canada* (2019) with respect to considerations of the treatment, along with the judgment of *AC v. Manitoba* (2009) concerning considerations specific to age and consent to treatment. With respect to s. 7, reasoning employed in *Carter* (2015) that a prohibition on MAiD infringes on the right to life is conceivable and compelling with respect to mature minors. A strong claim could likewise be made that Bill C-14 violates rights to liberty by invoking reasoning in *AC*, *Carter*, and *Truchon* that the law interferes with individuals' ability to make fundamental personal decisions about their bodily integrity and medical care. Security of the person would likewise be infringed upon, as the law forces individuals to endure intolerable suffering. Any s. 7 infringement is unlikely to be in accordance with the principles of fundamental justice as a result of being arbitrary due to the assumption that a mature minor cannot have capacity to make a medical treatment decision.

Meanwhile, in the context of s. 15, while age is an enumerated ground under the Charter, there is a tension between the premise of discrimination on the basis of age and the premise that age distinctions are acceptable as a common and necessary way of ordering society. Yet the analysis of *AC v. Manitoba* revealed that in the context of medical decision-making, while age distinctions may be used as an indicator to shift presumptions of capacity, firm age distinctions are a harmful and arbitrary use of regulation where age is an indicator of ability. In a challenge to Bill C-14, a mature minor claimant could argue that Bill C-14 imposes forced suffering on young people based on inaccurate stereotyping about their age. On the subject of whether Bill-C14 has an ameliorative purpose or effect, the trial judge in *Carter* found no application in this case due to the plaintiffs being less advantaged relative to Canadians able to die without attracting the attention of the Criminal Code. If found to have application to a s. 15 claim, excluding mature minors, a cohort with self-determination, from eligibility for MAiD would be invidious rather than ameliorative, inasmuch as it is based in unjustified paternalism and forces suffering upon them without adequate cause.

Finally, any violations to s. 7 or s. 15 cannot be saved by s. 1. The care and protection of children is a pressing and substantial legislative objective. Yet the care and protection of children is not rationally connected to the objective nor is it minimally impairing as mature minors are denied the

opportunity to demonstrate their capacity, a less restrictive regime addressing risks to the vulnerable. Lastly, denying mature minors the opportunity to prove their capacity does not advance the state's interest in overriding the Charter rights of mature minors who do not lack capacity or maturity, and therefore has a grossly disproportionate effect on mature minors.

4.6 Ongoing Issues

4.6.1 Access to Health Services and Charter Claims

As an issue centred on access to health services, there may be ongoing tension in s. 7 and s. 15 claims for mature minor access to MAiD. A difference between MAiD and refusal of life-sustaining treatment lies in the effect of the age distinction. In the context of refusal of life-saving treatment, age distinctions constitute an active interference, having the effect of forcing treatment on an individual. Meanwhile, interference resulting from an age distinction in the context of MAiD is inactive, having the effect of withholding a treatment which relieves suffering. Where the courts' approach to rights claims hinges on the prerequisite of state action or interference upon the rights of the claimant (Macfarlane, 2018, p 158), previous claims for access to MAiD have successfully framed state interference in terms of the "forced prolongation of life and accompanying suffering" (Carter v. Canada, 2015, par. 57–70; Truchon c. Procureur général du Canada, 2019, par. 521–522). By restricting access to MAiD, the law directly interferes with one's physical integrity, deprives one of the freedom and autonomy to make fundamental medical decisions affecting one's own body, deprives one of dignity, and forces suffering (Truchon c. Procureur général du Canada, 2019, par. 528–534).

In the broader landscape of s. 7 jurisprudence, claims on access to health services present a challenging to reconciling s. 7 Charter negative rights analysis in terms of state action or interference of rights holders, and the underlying issue about access to health services (Macfarlane, 2018, p 158). In the context of health policy, MAiD, along with abortion (*R. v. Morgentaler*, 1988) and supervised drug injection (*Canada (Attorney General) v. PHS Community Services Society*, 2011), share fundamental implications for the distinction between negative and positive rights in Charter challenges to federal criminal law (Macfarlane, 2018, 158). Where the harms of the impugned provision lie with the limits or prohibitions on access to health services, significant barriers to access due to state inaction pose an issue where "the conceptual distinction between negative and positive rights seems non-existent from the perspective of rights-holders" (Macfarlane, 2018, p 158). Thus, if

mature minors are permitted to access MAiD, there is concern that barriers to accessing treatment will remain where some mature minors may be unable to find a willing MAiD provider despite being eligible.

Meanwhile, s. 15 jurisprudence has had a complex and arguably convoluted evolution (Macfarlane, 2018, p 162), yielding conflicting guidance on the issue of equal access to health services. There have been cases where courts have recognized the effects of systemic discrimination along with positive obligations to provide health services (Macfarlane, 2018, p 162). Macfarlane raises the example of *Eldridge v. British Columbia AG* (1997) as the most relevant case, on the issue of whether deaf hospital patients suffered from adverse discrimination because the province's Medical Services Commission failed to provide access to sign language interpretation (Macfarlane, 2018, p 162). The SCC unanimously ruled that the failure to provide sign language interpretation services infringed s. 15(1), based on the reasoning that the provisions did not ensure that deaf persons benefit equally from a service offered to everyone (Macfarlane, 2018, p 162).

Although its s. 15 analysis is heavily criticized by scholars,³⁸ a conflicting position of positive obligations to provide health services was given in the SCC's ruling on *Auton v. British Columbia* (2004), where the SCC ruled that the province of British Columbia's refusal to fund an intensive behavioural therapy for children with autism did not violate s. 15 equality rights (Macfarlane, 2018, p 162). Rather than framing the issue as a question of what the public health system should provide (a question for the legislature), the SCC analyzed adverse-effects discrimination in terms of consistency with the overall purpose of the legislative scheme (Macfarlane, 2018, p 166). Characterizing the overall legislative regime as a partial health plan with governmental discretion over excluding medical services which are not "core" under the provincial health scheme, the SCC found that behavioural therapy services for children with autism was not an established benefit provided by law. Exclusion of behavioural therapy services is therefore unlikely to be discriminatory (Macfarlane, 2018, p 166). Moreover, the SCC did not establish that the government has excluded autistic children on the basis of their disability, by applying a narrow comparator group (Macfarlane, 2018, p 165).³⁹

³⁸ The SCC ruling in *Auton v. British Columbia* (2004) was criticized for not taking into consideration the impacts of autism, inflexible bureaucratic regimes, personal economic sacrifice, or progress under the treatment in the analysis (Macfarlane, 2018, p 167). Further, the logic in analyzing consistency with overall purpose of the provincial health scheme almost suggests that "if the purpose of the scheme provides for adverse effects discrimination, then it is not discriminatory" (Macfarlane, 2018, p 166).

³⁹ Where the claimants defined the comparator group in terms of non-disabled children and their parents, the SCC narrowed the comparator group to a person not suffering a mental disability (whether they have a

These issues point to a more generalized problem when it comes to balancing the negative rights of SCC claimants with the scope of the courts in securing access to health services. Chapter 6 of this dissertation will discuss differences between MAiD and withholding/withdrawing life-sustaining treatment in terms of whether there is a significant ethical distinction.

4.6.2 Best Interests, Welfare, and Self-Determination

Acknowledging that adolescents have an evolving right to autonomous decision-making, the majority judgment in *AC v. Manitoba* (2009) frames the best interests of adolescents in terms of a balance of principles of welfare and self-determination on a case-by-case basis (2009, par. 4). In the case of an adolescent with mature minor status, principles of welfare and autonomy may narrow considerably, and often collapse altogether in judgments of best interests (*AC v. Manitoba*, 2009, par. 84). Under this conception, when a minor has demonstrated capacity to make a treatment decision, any potential conflict between the two elements of a person's best interests – that is, welfare and self-determination – disappears. This is because the two concepts collapse together, and what is in the person's best interests is simply to respect the person's self-determination.

Yet in his dissenting judgment, Justice Binnie questions the majority conception of best interests, arguing that it does not resolve conflicts between welfare and self-determination. He raises the concern that this interpretation of best interests does not give the mature minor decision-making authority, instead giving the judiciary discretion to make a final decision on what is best for the mature minor, and merely gives the mature minor input into the decision. He cites *Starson v. Swayze* (2003) a case which also addresses questions of autonomy and protecting the vulnerable, claiming that the assessment of an individual's capacity and ability to appreciate a choice is completely distinct from an assessment of what is in that same individual's best interests from a medical perspective (*AC v. Manitoba*, 2009, par. 194). Collapsing welfare and self-determination may lead to an unintended conclusion that patients must make decisions which benefit them in order to self-determine, running the risk of interpreting disagreement with diagnosis or proposed treatment as evidence itself of incapacity (*AC v. Manitoba*, 2009, par. 194).

physical disability or are not disabled) seeking/receiving funding for a non-core therapy which is emergent, important for their present and future health, and only recently recognized as medically required (Macfarlane, 2018, p 165). This was heavily criticized for making a finding of discrimination very difficult and for avoiding a s. 1 analysis (Macfarlane, 2018, p 165).

In this way, by conflating welfare and self-determination, minors under 16 may still not be treated in the same manner as a minor who is 16 or older (*AC v. Manitoba*, 2009, par. 194). However much the weight of a minor’s self-determination increases according to their maturity level, even if a minor demonstrates capacity, “it still remains one consideration among others ... and is in no way determinative” (*AC v. Manitoba*, 2009, par. 194). Instead of a judicial interpretation which collapses self-determination and welfare, Justice Binnie proposes conceptualizing welfare and self-determination as distinct concepts, where a capable minor’s self-determination decisively trumps welfare considerations and clarifies the status of the mature minor as the decision-maker. Justice Binnie’s critique of the majority judgement in *AC v. Manitoba* (2009) can be used to argue that issues could persist in challenges to mature minor eligibility under Bill C-14 – where, in spite of sufficient maturity to provide consent, welfare considerations could prevail. Chapter 5 will further discuss best interests in the context of MAiD for mature minors.

Chapter 5

Best Interests and Welfare at the End of Life

5.1 Prologue: The Challenge of the Welfare Principle

In *AC v. Manitoba* (2009), the Supreme Court of Canada determined that adolescents under the age of 16 who wish to refuse life-saving treatment should be permitted to attempt to demonstrate their maturity. Their majority judgment reflected the principles expressed through articles 3 and 12 of the UN CRC, and argued that the best interests of mature minor are determined by collapsing considerations of welfare and self-determination principles altogether. This means that, for mature minors, the child's views become the controlling factor (*AC v. Manitoba*, 2009, par. 84). The dissenting opinion of Justice Binnie however, raised concerns that this interpretation does not resolve the conceptual tensions between welfare and self-determination; Justice Binnie claimed that the demonstration of mature minor capacity does not guarantee that mature minors have authority where their self-determination remains one consideration among others (*AC v. Manitoba*, 2009, par. 194).

This concern raises persisting questions about best interests and mature minors which relate to the “welfare principle,” that is, “the argument that a minor can only consent to care that would be of benefit” (Gilmore, 2011, p 390). The welfare principle challenges the law's guiding commitment to mature minors' interests in self-determination, particularly where they refuse beneficial or therapeutic treatment, or consent to treatment that is not beneficial or therapeutic (Gilmore, 2011, pp 389–390). There is legal uncertainty about the applicability of the welfare principle where consequences are very grave, and about whether, in the absence of a statutory requirement, considerations about treatment must still be routed through the best-interests test (Gilmore, 2011, p 391).

A related legal concern is the tension between the statutory and common law rights of a mature minor and the court's *parens patriae* jurisdiction, a legal mechanism to protect the vulnerable (Gilmore, 2011, p 393). The aim of *parens patriae* jurisdiction is “to protect minors when there are no parents or guardians to act in the minor's ‘best interests’, or when the court disagrees with parental decisions made on a minor's behalf” (Ferguson, 2004, p 19; Council of Canadian Academies, 2018, p 51). There have been conflicting judgments in the courts on whether a determination of capacity displaces *parens patriae* jurisdiction.⁴⁰ These persisting tensions in the legal landscape are mitigated

⁴⁰ In *Walker (Litigation Guardian of) v. Region 2 Hospital Corp.* Court of Appeal suggested that once it had determined that a minor was mature and decisionally capable, its *parens patriae* jurisdiction was displaced.

by a recognition that the threshold of sufficient decisional capacity varies with the gravity of the decision (Gilmore, p 392; Council of Canadian Academies, 2018, p 40; Committee for the Rights of the Child, 2009, p 9). Under this model, the decision to refuse life-sustaining treatment requires closer scrutiny to conclude that the minor is decisionally capable (Gilmore, p 392).

5.2 Introduction

If eligibility for MAiD were extended to mature minors, the impact of child welfare legislation would be unclear (Council of Canadian Academies, 2018, p 66). The decision to receive MAiD entails a degree of potential harm or risk similar to that of the decision to refuse treatment,⁴¹ where the outcome is certain death (Council of Canadian Academies, 2018, p 65). Thus, it is projected that mature minor requests would require a demonstration of the “ability to deeply understand and appreciate their situation, and make a mature, independent decision” (Council of Canadian Academies, 2018, pp 34, 66).

In 2013, Quebec’s Commission de droits de la personne et des droits de la jeunesse recommended regulation consistent with current consent laws for minors, but also acknowledged that the “specific and irreversible nature of medical aid in dying” should be taken into account (MacIntosh, 2016, S10). It is unclear if finality and irreversibility of the treatment should impact interpretations of best interests in the context of MAiD. Arguably, MAiD bears more risk than refusing life-sustaining treatment because it is possible that someone opting for MAiD might be mistaken in their decision (Singer, 2003, p 532). For instance, their suffering may be tolerable, their suffering may be relieved under circumstances acceptable to them, or they do not truly wish to pursue MAiD and are therefore not making a voluntary decision. In either situation, the person would be unable to change their mind once the procedure begins (Singer, 2003, p 532). Meanwhile, depending on the particular patient’s medical history, diagnosis, and prognosis without treatment, the decision to withdraw or refuse life-sustaining treatment may not always be final and irreversible. This risk may mean that considerations of child welfare should take precedence in interpreting best interests, resulting in a higher required threshold of capacity for self-determination to become the controlling factor. Thus, while a minor

Despite this suggestion, the Court of Appeal concluded that blood transfusions were not in a mature minor’s best interests (Gilmore, 2011, p 393). In other cases the courts reached the opposite conclusion, concluding that in the context of health care decisions, the common law *parens patriae* jurisdiction co-exists with and supplements legislation (Gilmore, 2011, pp 393–394).

⁴¹ Depending upon the clinical history, diagnosis, and expected prognosis, the refusal of life-saving treatment could vary from probable to certain death.

may be able to demonstrate a level of capacity sufficient to refuse life-saving treatment, this demonstration may not be sufficient to consent to MAiD. Alternatively, a heightened level of risk relative to refusal of life-sustaining treatment may completely preclude MAiD being in the best interests of the child.

These questions about the relationship between welfare, best interests, and MAiD rest on broader questions about welfare considerations in end-of-life decision-making. This chapter aims to inform the assessment of a mature minor's best interests in the context of a request for MAiD by applying tools used to interpret welfare in paediatric end-of-life decisions. The chapter begins with some background on the best-interests standard as articulated in Ontario's Health Care Consent Act, and explains how this standard is applied to decision-making on behalf of adults, children, and infants. From this background, I identify infants as a cohort where judgments on best interests are interpreted completely on the basis of welfare considerations, which are determined through projected clinical outcomes. An analysis of welfare in end-of-life decisions for infants therefore becomes the focus of this chapter – not to advocate that neonates ought to have access to MAiD, which is beyond the scope of this work, but rather to gain insight on how welfare is conceived when it comes to end-of-life decisions.

I then analyze the literature on clinical welfare judgments on paediatric end-of-life decisions from jurisdictions with a variety of stances on MAiD practices. The analysis focuses on clinical standards to evaluate welfare, and yields insights that prolonging life does not serve a child's welfare in cases of futility, where interventions are not recommended because of unlikely survival or unacceptable outcomes (Janvier et al., 2017, pE94). I lastly consider conflicts in end-of-life decision-making. This discussion draws on the insights of Ontario's Consent and Capacity Board (CCB), a quasi-legal tribunal for resolving disagreements in health care decision-making. This analysis reveals that CCB assessments of welfare are informed by considerations of both dignity and clinical outcome. The CCB affirm that considerations of dignity, suffering, and quality of life can overcome a presumption that prolonging life serves well-being, and that that risk should not be framed in terms of whether one dies, but rather "when and how, as well as what happens to a person until he or she dies" (Re EJD, 2007, p 21). These insights demonstrate that a decision to receive MAiD may be motivated by welfare considerations where it is motivated by severe pain and suffering, a low quality of life, and an unwillingness to endure continued indignities.

Along with the analysis in Chapter 4 demonstrating that a capable minor's self-determination becomes the controlling factor in determining their best interests, this chapter's findings reveal that MAiD can be in a child's best interests where they meet all other eligibility criteria. On the basis of these results, the chapter concludes that there is no significant ethical distinction between an adult request and a mature minor request under the legal framework. Recognizing that capacity is treatment-specific, Chapter 6 shifts focus. Rather than considering a general ethical distinction between adult and child access to MAiD, Chapter 6 instead contemplates a particular ethical distinction between mature minor consent to withdrawing or refusing life-sustaining treatment and mature minor consent to receive MAiD. This new framing of the issue asks whether there is some feature of MAiD such that mature minor access would be impermissible.

5.3 Part 1: Best Interests in Medical Decision-Making

5.3.1 The Health Care Consent Act

In Canada, the best-interests standard is articulated through provincial legislation governing healthcare decisions, and influences personal-care, financial, and child-protection decisions.⁴² If it is not possible to make a decision on the basis of the patient's known wishes or values and beliefs, the Substitute Decision Maker must make the decision most consistent with the patient's best interests (Coughlin, 2018). In Ontario, specific requirements to meet the best-interests standard are articulated in the Health Care Consent Act. Under section 21(2) of the Act, the best interests standard involves taking into consideration values and beliefs the incapable person held when capable and would still act on if capable, wishes regarding treatment expressed by the incapable person with respect to the treatment, and a number of factors surrounding the patient's well-being. These factors include: whether the treatment is likely to improve the patient's condition or well-being; prevent or reduce the extent to which the incapable person's condition or well-being is deteriorating; the likelihood of the patient's condition improving, remaining the same, deteriorating without the treatment; the

⁴² In Ontario, the requirement to act in the best interests of an incapable person is explicitly outlined in s. 21(2) of the The Health Care Consent Act (1996). Some decisions made under the The Substitute Decisions Act, and The Mental Health Act and The Child and Family Services Act, are subject to requirements to act in the best interests of the incapable person under the Health Care Consent Act (Queen's Printer of Ontario, 2000; Byrick and Walker-Renshaw, 2016; Council of Canadian Academies, 2018). The best-interests standard is also specifically articulated in The Child and Family Services Act in s. 110(4), which requires the courts to be satisfied that the treatment would be in the child's best interests before authorizing the treatment of an incapable child (Council of Canadian Academies, 2018).

proportionality of expected benefit to risk of harm of the treatment; and whether a less restrictive/intrusive treatment would be as beneficial as the proposed treatment (1996, c. 2, Sched. A, s. 21 (2)). Thus, the best interests standard under the Health Care Consent Act considers both the known wishes of the patient and the balance of risk and benefit of a proposed treatment and its alternatives.

5.3.2 Mechanism for Resolving Disagreements

In Ontario, patients, families, and health care providers who experience disagreements with respect to medical decision-making have recourse outside the courts through the Consent and Capacity Board (CCB). The CCB is an independent, quasi-judicial tribunal appointed by the province to adjudicate matters of capacity, consent, civil committal, and substitute decision-making (Consent and Capacity Board, 2012–2021, web). Under the Health Care Consent Act, various stakeholders involved in health care decision-making may apply to the CCB. Patients may apply to review findings of incapacity (Form A), to have a representative appointed for them (Form B), or (where the patient is incapable) to review admission to a treatment facility (Form F). Substitute decision-makers may apply for the CCB to clarify a patient’s prior capable wishes (Form D) or to override their wishes (Form E), or may apply to be appointed a patient’s representative (Form C). Health care professionals may apply for the CCB to evaluate whether the substitute decision-maker complied with rules for substitute decision-making (Form G) (Consent and Capacity Board, 2015, web). The CCB hears arguments from these parties and bases its rulings on the Health Care Consent Act and other similar legislation (Consent and Capacity Board, 2015, web).

5.3.3 Adults’ Interests Interpreted through Wishes

Best-interests assessments for adults are mainly guided by considerations of patient self-determination according to the patient’s known wishes, values, and beliefs. The Law Commission of Ontario, Ontario’s statutory framework for legal capacity and decision-making, interprets the best-interests standard in terms of “substituted judgement” (Law Commission of Ontario, 2017, p 64), that is, substitute decision-making. Rather than making decisions in terms of what they believe is best for the patient, substitute decisions are made from the incapable person’s point of view if they were able to understand and apply all of the relevant information to the decision (Law Commission of Ontario, 2017, p 64). Clinical considerations of the balance of probability of risk and benefit of the treatment to the incapable person are made through the lens of the incapable person’s “values and preferences

to the degree that they are known and understood” (Law Commission of Ontario, 2017, p 64). This includes considerations of the incapable person’s “prior capable wishes,” the values and beliefs they held while they were capable, and their current wishes (Law Commission of Ontario, 2017, p 64).⁴³ This lens may influence welfare-based evaluations of what is considered a “harm” or a “benefit,” as this is a matter of personal values and ought to be aligned to the patient’s known values and beliefs.

5.3.4 Children

The “best interest of the child” standard, central to both children’s rights frameworks and clinical paediatric decisions (Ross and Swota, 2017, p 187), balances two guiding principles. The first is to promote child welfare according to the child’s best interests (Archard and Skivenes, 2009, p 1). The concept of Best interests features in Article 3 of the UN Convention on the Rights of the Child (CRC):

In all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration.

The second other guiding principle is to allow the child to express his or her views on matters affecting his or her own interests to the extent warranted by their maturity, age, and understanding (Archard and Skivenes, 2009, p 1). This principle is articulated in Article 12 of the CRC:

1. States Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child.
2. For this purpose, the child shall in particular be provided the opportunity to be heard in any judicial and administrative proceedings affecting the child, either directly, or through a representative or an appropriate body, in a manner consistent with the procedural rules of national law.

In the clinical context, the best-interests standard acknowledges developing self-awareness and emerging self-determination of the child (Coughlin, 2018, web). As previously stated, there is no age of consent to treatment in Ontario. However, patients must be capable of giving consent to treatment (HCCA, 1996, c. 2, Sched. A, s. 10(1)), where consent is time- and treatment-specific (HCCA, 1996,

⁴³ This requirement applies to personal care decisions under the SDA and for all decisions under the Health Care Consent Act.

c. 2, Sched. A, s. 15). Under this legal framework, although children are presumed incapable, they may demonstrate sufficient capacities to make particular decisions (Buchanan and Brock, 1989, p 245).

Determining best interests in the context of medical treatment for an incapable child “involves weighing the benefits against the burdens of a proposed treatment in the context of what is known of the patient’s values, beliefs, family relationships and cultural norms” (Coughlin, 2018, web). Family relationships and cultural norms are relevant, as they inform the patient’s wishes, values, beliefs as well as their welfare considerations. Where children are incapable, legal decision-making authority rests with the SDM, typically the parents, who are often most highly ranked on the SDM hierarchy in the HCCA (1996, c. 2, Sched. A, s. 10(1)). Parents are usually the best positioned to act in the child’s best interests due to their knowledge of their child’s needs, and the fact that they are often their primary caregivers (Gillam and Sullivan, 2011, p 594). Yet, despite not having any legal decision-making authority, incapable children are still encouraged to have an active role in the decision-making process through giving assent. Assent is described as a way to inform the patient, show respect, allay their fears and develop decision-making capabilities (Lee et al., 2006, p 728). Yet while strong indicators of dissent should be given serious consideration, assent “is not a binding contract, and does not give the child ‘veto power’” (Lee et al., 2006, p 728).

5.3.5 Infants: A Question of Welfare

Interpreting the best interests of infants is unique, as they have not yet attained even a very limited capacity (Coughlin 2018, web), have never been autonomous, and have not developed any known wishes, values, or beliefs (Spence, 2000, p 1286). In the process of weighing the benefits and burdens of treatments, an infant’s best interests are clarified solely by interpreting what would best promote their welfare. Treatments therefore straightforwardly serve an infant’s interests where they lead to best outcomes as assessed in welfare terms; this is achieved by treatments aimed at providing comfort, promoting child development, avoiding undue pain, and that are not experimental (Coughlin, 2018, web; Spence, 2000, p 1287). Where the treatment or its outcomes are uncertain, or the treatment prolongs suffering or death, attention is focused on minimizing associated harms (Coughlin, 2018, web; Spence, 2000, p 1287).

Because the best interests of infants are interpreted by determining what is in their welfare, guidance on interpreting best interests in the case of infants and neonates may provide valuable insight into the welfare considerations of all children, including those who have a capacity to express

autonomous values and preferences. In the context of end-of-life care, where there are often uncertainties regarding what is in a patient's welfare, considering the best interests of infants and neonates may provide interpretations of welfare applicable to the issues of MAiD for mature minors.

5.4 Clinical Judgements of Welfare and End of Life

Judgments of clinical outcome are the determining factor in interpreting the welfare of infants, and are therefore a significant consideration in interpreting best interests at the end of life. In the Canadian context, Janvier et al. group fragile neonates into three decision-making categories. The first is the "Beneficial" category, where life-sustaining interventions are indicated because of good outcomes (Janvier et al. 2017, p F96). The second category is "Futile," where interventions are not recommended because of unlikely survival or unacceptable outcomes (Janvier et al., 2017, F96). The last category is the "Grey-Zone," where the outcomes do not clearly justify life-sustaining treatment or indicate against it (Janvier et al, 2017, p F96). Boundaries between such categories are drawn according to clinical interpretation of medical literature, but can also be influenced by family and clinician values (Janvier et al, 2017, p F96). The concept of futility is therefore significant in that it outlines that there are cases where continuing life-sustaining treatment does not serve an infant's welfare, and may in fact be harmful.

In the Dutch context, where euthanasia for severely ill newborns is regulated under strict conditions defined in the Groningen Protocol (2005), clinical outcomes similarly determine good practice on decisions to withhold/withdraw treatment. Eduard Verhagen and Pieter Sauer give three categories of end-of-life decisions for infants and newborns. The first category includes infants with no chance of survival, who often have a severe underlying disease (e.g., lung and kidney hypoplasia) and who die soon after birth, despite being provided with optimal care and the most current locally available methods (Verhagen and Sauer, 2005, p 959). The second category includes infants who have a very poor prognosis and depend on intensive care (e.g., infants with severe brain abnormalities or extensive organ damage caused by hypoxemia) (Verhagen and Sauer, 2005, p 959). Although patients in this second category may survive with a period of intensive treatment, their poor prognosis will persist, and they have a poor expected quality of life (Verhagen and Sauer, 2005, p 959). The last category are infants who are not dependent upon intensive medical treatment (though they may have once been dependent on intensive treatment), but who are predicted to have a poor quality of life with no hope of improvement (e.g., those with severe spina bifida) (Verhagen and Sauer, 2005, p 960).

These infants are predicted to experience what parents and medical experts would deem to be intolerable suffering (Verhagen and Sauer, 2005, pp 959–960).

Verhagen and Sauer determine that each category requires a different response from health care professionals. Futility as described by Janvier et al. is captured by categories 1 and 2. Withdrawing/withholding treatment is considered good practice for infants with no chance of survival, where the patient typically dies immediately upon withdrawal of intensive care (Verhagen and Sauer, 2005, p 960). Meanwhile, withdrawing treatment is acceptable in cases of poor prognosis and dependence on intensive care where the infant is not predicted to have an adequate quality of life (Verhagen and Sauer, 2005, p 960). Here, parents and health care professionals must agree that (continued) intensive treatment is not in the best interests of the child (Verhagen and Sauer, 2005, p 960).

In category 3, where infants are not dependent on intensive care, end-of-life treatment constitutes euthanasia rather than withholding or withdrawing life sustaining treatment. Verhagen and Sauer claim that euthanasia may be permissible in a limited number of such cases. The Groningen Protocol (2005) regulates the practice of euthanasia for severely ill newborns to prevent the unjustified ending of life (American College of Paediatricians 2014, web), defining strict conditions on when the use of sedatives and analgesics with the intention to hasten death of a neonate is acceptable (de Vos et al., 2011, p e1005). The Groningen Protocol gives five criteria that must be met for neonatal euthanasia to be ethically permissible. First, the diagnosis and prognosis must be certain (American College of Paediatricians, 2014, web; Verhagen and Sauer, 2005, p 960). Second, the infant must be enduring hopeless and unbearable suffering (American College of Paediatricians, 2014, web; Verhagen and Sauer, 2005, p 960). Third, there must be consensus among a team of physicians which includes one independent physician (Verhagen and Sauer, 2005, p 960) on the diagnosis, prognosis, and presence of unbearable suffering (American College of Paediatricians, 2014, web). Fourth, parents must give informed consent to the procedure (American College of Paediatricians, 2014, web; Verhagen and Sauer, 2005, p 960). Lastly, the procedure must be performed in accordance with the accepted medical standard, and there must be external legal oversight to retrospectively determine whether euthanasia was based on a justified decision and complied with procedure (American College of Paediatricians, 2014, web).

In addition to considerations of futility and poor prognosis, the Groningen Protocol also takes into consideration the degree of suffering experienced by the infant in evaluating welfare. While we can accept and rely upon the premise that adults will communicate when their suffering is unbearable,

infants cannot express their feelings to communicate their suffering through speech (Verhagen and Sauer, 2005, p 959). Infant pain scales are determined from changes in vital signs (blood pressure, heart rate, and breathing pattern) and observed behaviour (Verhagen and Sauer, 2005, p 959). Communications of infant suffering occur through different types of crying, movements, and reactions to feeding, where “experienced caregivers and parents are able to evaluate the degree of suffering in a newborn, as well as the degree of relief afforded by medication or other measures” (Verhagen and Sauer, 2005, p 959).

The question of euthanasia for neonates lies outside the scope of this dissertation, and this work will not consider the ethics of a request from a parent for their infant child to receive MAiD. Yet insights from the Dutch context on end-of-life decision-making for newborns and neonates help guide interpretations of welfare at the end of life, which may be applicable to the issue of MAiD for mature minors. The analysis reveals that prolonging of life is not inherently in a child’s welfare. Specifically, in cases of futility, decisions to prolong life may inhibit welfare rather than promote it, and ending life may serve welfare. Further, there are welfare considerations that may support a request for MAiD based on welfare, including unbearable suffering, no hope of improvement, and a poor quality of life.

5.5 Challenges in Interpreting Best Interests at the End of Life

The best-interests standard can be challenging to apply to decision-making, especially with regard to end-of-life decisions. Critically ill patients are often unable to communicate their wishes, values, and beliefs because they do not have the capacity to participate in treatment decisions or because they did not leave detailed instructions with their substitute decision-maker (Sibbald and Chidwick, 2010, p171.e1). Challenges in interpreting best interests often arise due to “disagreement between what the health care team believe their obligations to the patients are and what the SDM is claiming to be best for the patient” (Sibbald and Chidwick, 2010, p 171.e4). Families and health care providers often disagree about which party should have ultimate decision-making authority: families, who have knowledge of their loved one’s values and beliefs and are most personally impacted, or health care providers, “who have a greater knowledge of disease processes, prognoses, and therapeutic options” (Choong et al., 2010, E242).

In their review of Ontario CCB cases, Rob Sibbald and Paula Chidwick analyze themes surrounding best interests at the end of life, finding differences in interpreting the best-interests standard between SDMs and health care providers. These differences reflect the gap that exists more

generally between the public and health care professionals, where the public are more hopeful of a recovery where a patient is in a persistent vegetative state than health care professionals. Sibbald and Chidwick reference Jacobs et al. (2008): 61.3% of the public compared to only 20.2% of health care professionals believe that a miracle can save a person in a persistent vegetative state; 57.4% of the public compared to only 19.5% of trauma professionals felt that divine intervention can save a person when physicians think that treatment is futile (2010, p 171.e4).

Sibbald and Chidwick observed that religious values frequently arose among SDMs (2010, p 171.e4). A common view is that withdrawal of life-sustaining treatment is inappropriate because the decision about when someone should die is one for God to make (Sibbald and Chidwick, 2010, p171.e4). Another common religious position is that the presence of life indicates hope, thus requiring that all possible interventions be used to prolong life (Sibbald and Chidwick, 2010, p 171.e4). Sibbald and Chidwick additionally observed that in advocating for the best interests of the patient, SDMs emphasized their own values rather than the values of the patient (2010, p 171.e4). In many cases, SDMs believe that the decision before them is theirs to make according to their own values and beliefs (Sibbald and Chidwick, 2010, p 171.e5). This results in SDMs being burdened with the idea that refusing treatment will “kill their loved one” (Sibbald and Chidwick, 2010, p 171.e5). In contrast, clinician arguments were more focused on the clinical facts of the case with little focus on the patient’s values (Sibbald and Chidwick, 2010, p 171.e4).

CCB judgements reveal some clarity in interpreting best interests at the end of life. One insight is that the patient’s statements of values cannot be interpreted as prior expressed wishes; for example, the motto “Live, struggle, and do your best” was interpreted to be a statement of value and not a prior expressed wish (Sibbald and Chidwick, 2010, p 171.e5). Another insight is that religious values were a relevant consideration only where they were demonstrated to have been held by the patient (i.e., religious identity alone is insufficient to establish that the patient holds specific religious values) (Sibbald and Chidwick, 2010, p 171.e5).

Lastly, a judgment in a patient’s best interests must adequately take into account the clinical prognosis and the effect (including negative effects) of proposed treatment (Sibbald and Chidwick, 2010, p 171.e5). The CCB interpreted that mere life does not constitute best interests, as the patient’s “condition” refers to their overall health rather than their diagnosis (Sibbald and Chidwick, 2010, p 171.e5). This involves considerations of the effects of cascading treatments on the patient, as well as the patient’s dignity as part of their well-being (Sibbald and Chidwick, 2010, p 171.e5). Thus, in

cases of futility, where medical interventions will not improve or change the patient's condition for the better, active, aggressive, or life-sustaining treatments may fall within the standard of care but may not be in the best interests of the patient (Sibbald and Chidwick, 2010, p 171.e6).

5.5.1 Clarifying Welfare Considerations: Best Interests of Infants and Neonates

There is an international literature on disagreements in end-of-life decision-making for infants. In a survey of pediatric specialists' approaches to end-of-life decision-making, de Vos et al. found that conflicts in end-of-life decision-making occur regularly between parents and health care providers, and among health care providers (2011, p e1010). Differing views on prognosis and treatment modalities are the main causes of intra-team conflicts (de Vos et al., 2011, p e1010). A study by Dombrecht et al. found that health care providers report easier decisions where a poor prognosis is certain and becomes evident quickly, and neonatologists articulated the importance of certainty that all options have been explored before considering an end-of-life decision (2019, p 6). Meanwhile, fluctuations in health create differences in opinion regarding health or future quality of life (Dombrecht, 2019, p 6). End-of-life decisions are therefore challenging because they are medically complex and seldom provide certain prognoses (de Vos et al., 2011, p e1009; Schaller and Kessler, 2006, p 69). Further, where the child has a rapidly deteriorating condition, decisions to withdraw treatment are under a time constraint (de Vos et al., 2011, p e1009; Schaller and Kessler, 2006, p 69). There are additionally concerns about whether judgments of futility are accurate in light of uncertainties in end-of-life decisions. Janvier et al. noted that in a study of very and moderately preterm children, the EPITAGE-2 cohort,⁴⁴ many neonates were judged to be futile, where life-sustaining treatment was not considered, though they ought to have been judged to be in the grey zone (2017, F96).

While there are strong ethical obligations to inform and involve parents in their child's decision-making (Gillam and Sullivan, 2011, p 594; Janvier et al., 2017, F96), there is also a recognition that parental decisions do not have absolute ethical weight, and can be overridden in circumstances where parental decisions could cause significant harm to their child (Gillam and Sullivan, 2011, p 594). Between the parents and the team, conflicts are based on differing views of prognoses (de Vos et al., 2011, p e1010). Contrary to the team, parents are either more hopeful of their child's survival, believed that there were more treatment options, or had a more positive view of the infant's quality of

⁴⁴ The EPITAGE-2 cohort is a French national study which aims to examine short- and long-term outcomes of very preterm children and their determinants (Ancel et al., 2014, p 2).

life (de Vos et al., 2011, p e1009). In some cases, parents had strong moral objections to the end-of-life decision due to religious conviction (de Vos et al., 2011, p e 1009; Michelson et al., 2009, p 991). In a study by Michelson et al., parents reported giving less weight to physician-estimated prognosis in their decision-making, and a small proportion of parents (13%) would never consider withdrawing life-sustaining therapy (2009, p 991). Conflicts are often resolved with more time, intensifying discussions, or getting a second opinion (de Vos et al., 2011, p e 1010).

5.5.2 Interpretations of Paediatric Best Interests: The CCB

In Ontario, seven cases involving paediatric decisions at the end of life were brought to the CCB between 1996 and 2015: *Re EJG* (2007), *L* (2008), *Re C* (2009), *Re W* (2009), *Re JM* (2011), *Re CN* (2014), and *Re SS* (2015). In all cases, a physician brought a Form G application to the CCB to evaluate whether parents of the patient complied with the rules for substitute decision-making. In five of seven cases the CCB ordered treatment, while in the other two cases the applications were dismissed. In four cases, applications challenged parental refusal of a proposed treatment plan to withdraw life-sustaining treatment, while in the other three cases the applications challenged parental refusal of treatment within the standard of care. Further, in all seven cases, the CCB judgments provided insight into interpreting the best interests of the child. A table summarizing the progress and outcomes of paediatric end-of-life CCB cases can be accessed on the Western University Health Ethics and Policy Lab website (Sibbald, NDA, web). Summaries of each case can be found in Appendix 1.

5.5.2.1 End-of-Life Issues

In each case, there was disagreement between the patient and family regarding the prognosis. In five of seven cases, the disagreement centred on the medical futility of further treatments, where parents did not agree with health care professionals that further treatment would be futile. In some cases, parental disagreement resulted from a distrust of medical opinions of prognosis (three out of seven). The question of whether parents were sufficiently informed was at issue in two of seven cases – whether the SDMs did not receive all relevant information, or were not aware of the significance of information. In other cases, parents' views of what would advance their child's welfare were unaltered by contrary medical evidence (four out of seven). For instance, contrary to medical opinion that JM had a poor prognosis and quality of life, JM's parents believed that JM was breathing and

responsive, that his sister's condition was more severe, and thus wanted JM home for whatever time he had.

Parents demonstrated disagreement with prognoses on the basis of religious beliefs in four of seven. In *Re EJG*, the parents believed that "God would heal their son." Another perspective given by parents in *R: JM* was that treatment ought to be continued because God will determine when their child dies. Yet deference to "God's will" does not always underlie parental decisions to continue life-sustaining treatment. In *Re C*, parents refused medically indicated treatment on the basis that they "did not want to use technology to interfere with God's plan." Despite this pattern, the case of *Re SS* demonstrated that while parents may hold religious beliefs, such beliefs do not necessarily influence decision-making.

Questions of suffering, dignity, and quality of life were raised by the parents and the care team. In *Re EJG* there was debate about whether EJG could experience suffering if his pain was being managed; the care team argued that EJG experienced existential suffering, while EJG's parents argued that he could not suffer. In EJG's case, the CCB also considered the impact of "constant invasions and humiliations to which his inert body was subject" on EJG's dignity. The CCB likewise gave similar consideration for SS's dignity and suffering. In particular, whether SS was experiencing sufficient pain to deprive him of the simple pleasures (such as recognizing and enjoying the presence of his parents), and whether the experience of lying in a hospital bed hooked up to many machines with tubes impacted SS's dignity were considered. In *Re C*, C's parents raised concerns on the effects of prolonged hospitalization on quality of life, as well as the effects of not being raised by her family.

5.5.2.2 CCB Judgments

In five of seven judgments, the CCB found that the parents were not making decisions according to the child's best interests.⁴⁵ The CCB asserted that the children in these cases had not yet developed their own values and beliefs, and found that in some cases parents made decisions in accordance with their own values as opposed to those of their child. This includes religious values. *Re EJG* established that EJG's parents were entitled to give primary importance to their unrelenting faith in divine

⁴⁵ The parents were found not to have acted in the child's best interests in *Re EJG*, *Re L*, *Re JM*, *Re C*, and *Re W*. The Board found that parents acted in accordance with the child's best interests in *Re SS*. In *Re CN*, the Board did not make a determination whether the parent's wish to maintain all treatments was in the best interests of the child, but did note that the lack of communication and trust between the team and the parents was not in CN's best interests.

intervention in making their own treatment decisions, but that EJG did not have any values or beliefs. This was invoked in *Re JM*, where the CCB affirmed that JM's parents could not ascribe their views to their child. Likewise, in *Re W* the CCB determined that M's parent's religious beliefs that M's life rested in God's hands and that "life is better in heaven than on earth" could not be attributed to M as M had no values.

The CCB ruled in favour of withdrawing life-sustaining treatment in two of four cases which addressed futility. In both *Re EJG* and *Re JM*, the CCB determined that no treatment would improve the underlying condition, but that further treatment could extend the patients' lives for a longer period of time with a potentially negative impact on quality of life. The CCB found that in consideration of EJG's well-being, the negative effects of the continued invasions and humiliations of further treatment overrode the presumption that continuing life served EJG's well-being, where EJG had no countervailing values or beliefs to those factors. In *Re JM*, the CCB determined that JM should be allowed to die with dignity and that his best interests were served by withdrawing aggressive treatment. Meanwhile, in *Re SS*, the CCB found that the parents did act in SS's best interests, determining that his condition and well-being neither improved nor deteriorated with treatment, and did not find "clear, cogent, and compelling evidence that SS suffered pain to the extent that discontinuation of life" should be considered. In *Re CN*, while the Board did not challenge the team's evidence that withdrawing critical care in favour of palliative and comfort care measures served CN's best interests, the Board did not order consent to withdraw treatment, as CN's parents were not sufficiently informed by the team to give informed consent.

The CCB invoked two court cases to evaluate well-being in cases of futility: *Airedale NHS Trust v. Bland* (1993), a British House of Lords case on the decision to withhold treatment from a patient in a persistent vegetative state, and *Scardoni v. Hawryluck* (2004), an Ontario Superior Court case about the decision to withdraw intensive care from a patient with advanced Alzheimer's disease. These cases were applied in making the judgment that "well-being involved more than mere life itself" (*Scardoni v. Hawryluck*, 2004, par. 45–50), and mere prolongation at all costs of the life of a patient with no hope of any recovery is not necessarily in their best interests (*Re EJG*, 2007, pp 14–16). Further, the CCB asserted that an objective judgment of best interests includes more than a status of physical illness (*Scardoni v. Hawryluck*, 2004, par. 45–50), requiring expert opinion and considerations of quality of life, pain, and suffering, as well as less tangible considerations of dignity

and humanity (i.e., a right to avoid unnecessary humiliation and the degrading invasion of the body) (Re EJM, 2007, pp 14–16)).

The CCB also commented on evaluations of risks and benefits when considering the futility of further treatment. In *Re EJM*, the CCB contemplated how best to frame risk and benefits when considering withdrawal of life-sustaining treatment, asking whether death is the greatest risk. They determined that risks should not be framed in terms of whether one dies, but rather “when and how, as well as what happens to a person until he or she dies.” Further, the CCB found that considerations of the “when” and “how” of death are factors which inform “well-being,” which should be conceived broadly to include questions of dignity.

Thus CCB judgments on paediatric end-of-life decisions yield valuable insights on interpreting the best interests of the child. All seven cases required that best interests be analyzed exclusively in terms of welfare considerations. Where an incapable child has no previously expressed wishes values or beliefs, the values of the parents (such as religious values) cannot be ascribed to the child. Welfare in the context of the best interests of the child is principally understood in terms of the clinical judgments of the risks and benefits of the proposed treatment. In cases of futility, allowing a natural death by withdrawing aggressive treatment has been interpreted as advancing a child’s welfare where there is a poor prognosis, high estimated suffering, and a poor projected quality of life.

5.6 Conclusion

The potential impact of child welfare legislation on MAiD for mature minors is unclear (Council of Canadian Academies, 2018, p 66). Acknowledging that the best interests of the child are interpreted according to both the child’s self-determination and their welfare, this chapter builds on analysis in Chapter 4 supporting mature minor access to MAiD on grounds that they can self-determine, focusing on the second component of best interests: whether welfare considerations support MAiD for mature minors. Reviewing statutory best interests under Ontario’s Health Care Consent Act revealed that the best interests of infants are interpreted according to their welfare, by determining treatment outcomes. Hence, an analysis of welfare considerations for infants at the end of life provides interpretations of welfare applicable to the issues of MAiD for mature minors.

The analysis finds that welfare in end-of-life decisions for infants is principally a clinical judgment. Clinical judgments of futility illustrate that prolonging life may inhibit rather than promote child’s welfare, and that quality of life and suffering are welfare considerations in end-of-life decisions. CCB

judgments on end-of-life decisions generally, and paediatric end-of-life cases specifically, reinforce this notion. Moreover, the CCB judgments reveal that judgments of welfare include well-being, which is more broad than the status of one's physical illness and incorporates less tangible considerations such as dignity and humanity. Examining the prospect of a mature minor's request for MAiD being rejected on the basis of clinical judgments of their welfare, the analysis of the best interests of infants reveals that in many cases clinical judgment about welfare are likely to support a MAiD request rather than reject it.

An interesting judgment made in *Re EJG* indicates that death should not be conceived as the greatest risk. The CCB also framed risks and benefits in terms of end-of-life decisions in terms of when, how, and what happens to a person when they die, rather than whether one dies. This framing of risk may have implications for arguments that MAiD entails more risk than withholding/withdrawing life-sustaining treatment. Yet the judgment is raised in the context of withdrawal of life-sustaining treatment, and it is unclear whether this framing is applicable in the case of MAiD. This uncertainty relates to a broader question asked in the Council of Canadian Academies Report, where the CCA noted that the applicability of cases of withholding and withdrawing treatment to MAiD “depends, in part, on whether one views withholding and withdrawing treatment as ethically distinct from MAiD.” These questions will be addressed in the next chapter, which gives a comparative analysis of the ethical features of withdrawing life-sustaining treatment and of MAiD.

Chapter 6

MAiD and Refusal of Life-Sustaining Treatment: Is There an Ethical Distinction?

6.1 Prologue

Chapter 4 analyzed the question of whether adolescents are sufficiently capable to request MAiD, asking: Should minors be prohibited from MAiD on the basis of their age? This question was addressed with respect to refusing life-saving treatment in *AC v. Manitoba* (2009), where the Supreme Court of Canada determined that the ability to make treatment decisions should be calibrated according to maturity rather than age, and that a minor under the age of 16 should have the opportunity to prove that they “have sufficient maturity to direct the course of their medical treatment” (*AC v. Manitoba*, 2009, par. 25). In the Council of Canadian Academies report, the Expert Panel Working Group on MAiD for Mature Minors found that “some minors have the cognitive and emotional abilities to make critical healthcare decisions, including end-of-life choices” (2018, p 87), and that the maturity of adolescents should be assessed on a case-by-case basis (2018, p 87). In fact, some authors argue that there are some cases where minors may be more mature and capable of making end-of-life decisions than some adults, and are the best judges of what would further their interests, especially where they face serious illnesses (Cuman and Gastmans, 2017, p 841; Cohen-Almagor, 2018, p 231). In such cases, the minor’s decision must be authoritative (i.e., it is responsive to reason, and does not relinquish responsibility and defer the decision to others), respected, and should not be subject to being overruled (Bovens, 2015, p 310; Cuman and Gastmans, 2017, p 841).

Yet age distinctions still have a role in medical decision-making. Although age alone cannot predict minors’ capacity to provide informed consent for medical treatment, it can provide some generalizations about the development of decision-making skills (Council of Canadian Academies, 2018, p 87). Age distinctions in medical decision-making are therefore fluid, used as an indicator to shift presumptions of capacity (*AC v. Manitoba*, 2009, par. 111). Individuals below the age of consent are presumed to lack capacity unless proven otherwise, and those above the age of consent are presumed to be capable unless proven otherwise (*AC v. Manitoba*, 2009, par. 111).

For minors who overcome their presumption of incapacity, there are persisting welfare concerns where the consequences of the treatment decisions are grave. Chapter 5 likewise considered whether there are welfare considerations which may override a mature minor’s right to self-determination in

the context of MAiD. Such considerations are expressed by the “welfare principle,” which challenges the law’s guiding commitment to self-determination in cases where mature minors refuse beneficial or therapeutic treatment, or consent to treatment that is not beneficial or therapeutic (Gilmore, pp 389–390). Through giving an analysis of the interpretation of statutory best interest at the end of life, the chapter concluded that prolonging life does not always promote welfare, and that prolonging life may be harmful due to considerations of quality of life, suffering, dignity, and humanity. Thus, exercising one’s self-determination to request MAiD does not necessarily conflict with welfare considerations.

If we accept that children can demonstrate the capacity to make autonomous treatment decisions, and that they can use this capacity to make end-of-life decisions, including refusing life-sustaining treatment, then there is likely a small subset of adolescents who could, in theory, qualify for MAiD. While mature minors might in principle be eligible, the numbers of mature minors who qualify for MAiD are likely to be small. In the Council of Canadian Academies Report, the expert panel on mature minor requests predicted that “the number of MAiD inquiries or requests from minors themselves is likely to be small, but by no means trivial” (Council of Canadian Academies, 2018, p 109).⁴⁶ Minor eligibility for euthanasia is rare in the Netherlands and Belgium. From 2002 to 2018, 13 notifications of euthanasia involving minors were reported to Regional Review Committees: eleven aged 16–18, one aged 14, and one aged 12 (Council of Canadian Academies, 2018, p 111). Since 2014, there have been three reported cases of paediatric euthanasia in Belgium: two in 2016 and one in 2017. The patients were aged 17, 11, and 9 (Counsel of Canadian Academies, 2018, p 113).

In order to qualify for MAiD, the minor would have to overcome their presumption of incapacity, and demonstrate sufficient agency to make critical health care decisions. Where found fully capable, a mature minor’s self-determination becomes the controlling factor, and their request would be an exercise of their self-determination. Further, a minor’s request would be least subject to a challenge grounded in welfare, where considerations of quality of life, suffering, and dignity indicate that prolonging life would be harmful. This condition is likely met where a mature minor has a grievous and irredeemable medical condition, where they have a serious and incurable illness, disease or

⁴⁶ The Expert Panel Working Group on MAiD for Mature Minors commented on a 2016 survey from the Canadian Paediatric Surveillance Program, which asked how often respondents engaged in exploratory discussions or received requests for MAiD (Council of Canadian Academies, 2018, p 110). Respondents reported 60 exploratory discussions, and 17 requests from paediatric patients who were mostly aged 14–18 years (Council of Canadian Academies, 2018, p 110). Still, the Expert Panel Working Group acknowledged the possibility of increasing requests (Council of Canadian Academies, 2018, p 110).

disability, where they are in an advanced state of irreversible decline in capability, where they experience intolerable and enduring physical or psychological suffering, and where a natural death has become reasonably foreseeable (Bill C-14).

But this conclusion that mature minors can qualify for MAiD is too quick. After all, it is based on an appeal to the idea, affirmed in *AC v. Manitoba*, that mature minors can refuse life-sustaining treatment. This raises the question of whether there is some relevant ethical factor distinguishing the decision to receive MAiD from the decision to refuse life-saving treatment, such that the latter is permissible and the former is impermissible.

6.2 Introduction

This chapter will compare the mature minor decision to receive MAiD with other end-of-life decisions, including the choice to refuse life-sustaining treatment. In this chapter, the refusal of life-sustaining treatment will be discussed in terms of a case similar to that at issue in *AC v. Manitoba* (2009) – one where the treatment will cure or significantly prolong life. This comparison targets the key question on whether a request for MAiD requires a different response from other end-of-life decisions that mature minors can make (Council of Canadian Academies, 2018, p 81) based on a fundamental ethical distinction (Council of Canadian Academies, 2018, p 81; Kaczor, 2016, p 57). The trial judge in *Carter* (2012) found that “no ethical distinction between physician-assisted death and other end-of-life practices whose outcome is highly likely to be death” (par. 335–339). This judgment, however, is specific to questions of adult requests for MAiD, and does not consider factors specific to mature minors (Council of Canadian Academies, 2018, p 81).

The chapter begins by examining positions for and against mature minor access to MAiD based on the argument from consistency. While the position for mature minor access for MAiD claims that granting access furthers consistency because there is no ethical difference between MAiD and other end-of-life decisions, the position against makes an ethical distinction. The consistency argument against MAiD for mature minors has two parts. First, there is a morally relevant difference between MAiD and refusing life-sustaining treatment, where MAiD is the most “weighty” decision one can make. Second, it is inconsistent to allow minors to make this life-and-death decision while being unable to make “less serious” decisions. This difference between intentionally causing a death and merely allowing a foreseen death to happen, opponents argue, is grounded in the doctrine of double effect, which presumes that death is inherently harmful and that this harm impacts the informed consent process.

Finally, I argue that the consistency argument against allowing MAiD fails because the claim that MAiD is a “weightier” decision is mistaken based on two premises:

(1) That life is not intrinsically valuable, and that the determination of whether death is a harm or a benefit is dependent on the person’s evaluation of the expected quality and duration of their continued life.

(2) Life has experiential and critical value,⁴⁷ and to intentionally request assistance to end one's life is not merely an "objective" clinical matter, but also involves careful considerations of personal "subjective" value.

Based on this analysis, these factors support the following conclusion: refusing life-sustaining treatment, a choice to die where one could otherwise live, is a weightier decision than the decision to receive MAiD, a choice of how one dies where death is unavoidable. Thus, a distinction permitting a minor to refuse life-sustaining treatment while refusing to allow minors to consent to MAiD treats minors inconsistently.

6.3 The Argument from Consistency: A Question of an Ethical Distinction

Noting that minors are permitted to make certain kinds of decisions while being prohibited from making other kinds of decisions, arguments from consistency compare permitted and prohibited decisions in order to determine whether they are consistent. If one kind of decision is permitted and another is prohibited, there must be a morally significant distinction between them to explain that difference in treatment. These arguments have been used to argue both for and against mature minor access to MAiD. Support for MAiD is grounded in the premise that minors are already permitted to make other end-of-life decisions, such as treatment refusal, pain management, and terminal sedation, and that (at least in the adult context) there is no ethical distinction between MAiD and these treatments (*Carter v. Canada*, 2012, par. 235, 335). This is because the ethical framework which justifies other end-of-life treatments also justifies MAiD: decisions must be made by capable patients and serve their best interests by preventing or avoiding suffering (*Carter v. Canada*, 2012, par. 234). Thus, the distinction is not justified by ethical considerations of the suffering or capacity of the minor, but rather the amoral consideration of dependence on life-sustaining treatment (*Council of Canadian Academies*, 2018, p 121; *Guichon et al.*, 2017, pp 798–799). In the paediatric context, arguments against an ethical distinction between MAiD and palliative sedation are bolstered by practical similarities between the two practices. In a study on euthanasia in children in the Netherlands, *Rietjens et al.* found that where life expectancy exceeds one week, the use of palliative sedation may be difficult to differentiate from euthanasia due to its life-shortening effect (2014, p 1259).

⁴⁷ L.W. Sumner references Ronald Dworkin to provide an account of experiential and critical interests (*Sumner*, 2011, p 120).

Children are already permitted to make far-reaching medical decisions which affect the timing of one's death, including the decision to refuse life-sustaining treatment (Raus, 2016, p 310; Bovens, 2015, pp 630–631). A prohibition of MAiD does not shield minors from making these difficult decisions during the course of their illness (Raus, 2016, p 310). If there is no ethical distinction between MAiD and other end-of-life options, mature minors ought to likewise be able to make a decision for MAiD. As an additional recourse, MAiD may be a preferred alternative to other end-of-life options in certain cases. For instance, a decision of whether to refuse a life-sustaining tracheostomy or assisted ventilation presents a cruel choice between receiving unwanted medical treatment, and a difficult death due to asphyxiation (Guichon et al., 2017, p 799). Further, some clinicians maintain that palliative sedation does not always relieve suffering (Rietjens et al., 2014, p 1259; *Carter v. Canada*, 2012, par. 242). Meanwhile, practices such as dying from a lack of food or fluids may entail additional negative experiences in the dying process, including severe pain and indignity (Raus, 2016, p 310).

Yet opponents of extending MAiD access to mature minors argue that minors are commonly and justifiably prohibited from making many kinds of decisions, and are treated differently from adults for their protection. Consistency is therefore furthered by prohibiting minors from accessing MAiD as well. Regardless of their maturity, minors are prohibited from voting and performing other duties of citizenship, entering military service, having sexual intercourse, getting married and raising children, drinking alcohol and smoking tobacco, and dropping out of school (Cohen-Almagor, 2018, p 238; Kaczor, 2016, p 57). Minors are also held to a different standard of accountability for their decisions in the criminal justice system, and receive different sentencing than adults (Cohen-Almagor, 2018, p 238; Kaczor, 2016, p 57). Such prohibitions presumably acknowledge that weightier decisions are better reserved to a later stage of life, and require a certain degree of mental and physical, maturity, and responsibility (Cohen-Almagor, 2018, p 238).

This argument is partially refuted for treating minors arbitrarily (Chambaere et al., 2014, p 1258), “fail[ing] to explain how such characteristics of maturity can be acquired magically on the stroke of midnight on a child's eighteenth birthday” (Samanta, 2015, p 5). Chapter 4 of this work considered arbitrariness in analyzing *AC v. Manitoba*, where the majority judgment determined that the use of age distinctions is often arbitrary, and can only be justified where the chosen age is reasonably related to the legislative goal of the distinction (2009, par. 110). In particular, the use of age distinctions on matters of skill or judgment risk were acknowledged to risk imposing disabilities on minors based on

inaccurate stereotyping in a dissenting opinion (AC v. Manitoba, 2009, par. 31). MAiD is also a decision of self-regarding conduct, where the choice only risks of harm to the self,⁴⁸ as opposed to decisions to drive or possess weapons, which risk harm to others (Cohen-Almagor, 2018, p 238).

Yet the argument maintains that mature minor requests for MAiD require added scrutiny and that minors should be held to a different standard in the case of life-and-death decisions. The decision to die is distinguished from other decisions, “as virtually all other choices may be reversed or mitigated” (Kaczor, 2016, p 57), and moreover, because “death brings an end to claiming all other rights” (Cohen-Almagor, 2018, p 238). Under this reasoning, permitting MAiD would create an inconsistency such that some adolescents could make an irreversible life-and-death decision, but could not make a host of other “less serious” decisions (Raus, 2016, p 310).

6.4 Appeal to a Distinction Based on the Argument from Weightiness

At the core of this persisting issue is the argument from weightiness. Under this argument, MAiD is the most weighty decision possible (Bovens, 2015, p 630), where, in addition to the capacity to make a treatment decision, there are a number of considerations grounded in personal values. These personal considerations require a capacity for wisdom and self-reflectiveness which develops over the life cycle (Siegel et al., 2014, p 1259). As a result, proponents of the argument from weightiness argue that older adults are better equipped to make such decisions of great magnitude, whereas children do not have sufficient experience to make a sound decision (Siegel et al., 2014, p 1259; Siegel et al., 2014, p 1963).

The personal reasons described in the argument for weightiness recognize that “adults choose euthanasia for reasons that go beyond pain” (Siegel et al., 2014, p 1963) which include fear of a loss of control, losing personal integrity, not wanting to burden their families, or the desire not to spend their final days of life fully sedated (Dong, 2018, p 12; Siegel et al., 2014, p 1963). Siegel et al. observe that in many cases these reasons are based on experience, whether the decision is made after witnessing a loved one expressing a loss of dignity, or because they refuse terminal sedation based on a full understanding of the treatment (2014, p 1963). These factors may be a barrier to informed consent in the case of children, who may not understand such complexities of the decision (Dong, 2018, p 12), in spite of being able to grasp the medical considerations in the context of their illness.

⁴⁸ While MAiD may negatively affect a mature minor’s loved ones, this consideration should not impact rights to autonomy in medical decision-making (Cohen-Almagor, 2018, p 238).

Moreover, without adequate experience, children lack the intellectual capacity to develop a sophisticated preference in refusing palliative interventions (Siegel et al., 2014, p 1963). The argument from weightiness therefore reasons that demonstrated capacity to request MAiD requires that one's wishes, values, and beliefs are informed by a degree of life experience which cannot be achieved in childhood.

An ongoing question is whether there is a fundamental difference in weightiness between the decision for MAiD and decisions to refuse life-sustaining treatment, for pain management, and for palliative sedation (Kaczor, 2016, p 57; Bovens, 2015, pp 630–631). Rather than focusing on the nature of the treatments themselves, opponents of MAiD maintain that the nature of the decisions are ethically distinct, and warrant added protection for minors who request MAiD. The refusal of life-sustaining treatment is framed as a decision to remove burdensome treatment, while MAiD is exceptional in that it entails a choice to intentionally and deliberately end one's life (Kaczor, 2016, p 57; Siegel et al., 2014, p 1259). These factors relate to concerns that, despite the fact that capacity is not dependent on age, minors require added protection when it comes to the informed-consent process for MAiD, which could justify being held to a different standard than adults (Council of Canadian Academies, 2018, p 82).

6.5 Application of the Doctrine of Double Effect to MAiD and Refusing Life-Sustaining Treatment

The comparison of MAiD with other end-of-life decisions is sometimes framed in terms of an ethical distinction between doing and allowing, which rests on the question of intentionally causing death. This issue is typically discussed in terms of the Doctrine of Double Effect, which maintains a significant ethical distinction between intending and foreseeing. The Doctrine of Double Effect is typically applied in comparing palliative sedations and MAiD. Proponents of this view describe the intentions of palliative sedation to render the patient unconscious and ease the patient's pain, motivated by compassion and respect. While death is the likely outcome of palliative sedation, it is not the intended outcome. Further, palliative sedation itself is not the cause of death; instead, the patient's death is caused by their disease. In contrast, MAiD is intended to cause death and is itself the cause of death. Some opponents of MAiD think that this difference between outcomes that are intended as opposed to merely foreseen is morally significant. It grounds the Doctrine of Double Effect, the claim that some outcomes are permissible to allow but impermissible to intentionally bring about (Sumner, 2011, p 57). This is distinguished from the intention of MAiD to directly cause death.

The Doctrine of Double Effect requires three conditions to be satisfied for the harm to be permissible: (1) the agent intends for the action to create benefit rather than harm, (2) the harm would not occur if not for that action (i.e., a “but for” cause), and (3) there is a proportionately serious reason for bringing about the bad effect (Sumner, 2011, p 57).

The Doctrine of Double Effect has also been evoked to compare refusal of life-saving treatment and MAiD. This comparison is based in the observation that refusal of life-sustaining treatment is framed as a negative right grounded in bodily integrity, while MAiD is framed in terms of positive rights such as autonomy and dignity (Raus, 2016, p 310). When it comes to refusing life-sustaining treatment, the fact that treating a competent patient against their will constitutes unwanted bodily invasion (Raus, 2016, p 310) grounds intentions to respect a patient’s wishes and the right to decide which therapies they are willing to accept (Sanchini et al., 2014, p 3). Meanwhile, positive rights have been considered to carry less moral weight, and therefore could justify a request being ignored (Raus, 2016, p 310). Likewise, framing the action in terms of respecting non-interference has a bearing on the cause of death. When a patient dies after refusing life-sustaining treatment, proponents of the Doctrine of Double Effect claim that they die from an underlying fatal disease⁴⁹ (Keown, 2014, p 6). In contrast, the death of a patient who receives MAiD is caused by the medication (Keown, 2014, p 6).

The argument that there is a significant moral distinction between doing and allowing is, however, widely criticized. L.W. Sumner, for instance, questions an ethical distinction between intended and foreseen effects, noting that both treatments are justified by outcomes of relieved suffering, and death outweighing outcomes of suffering and continued life (2011, p 70). On Sumner’s account, ethical distinctions are collapsed due to a number of principal factors. Sumner challenges the premise that the intended outcomes of other end-of-life treatments can be distinguished from the intended outcomes of MAiD (i.e., Sumner claims there is no clear line between permissible and impermissible kinds of treatment) (Sumner, 2011, pp 17–18). Further, in end-of-life decision-making, the effects of an action, whether harmful or not, have been consented to by the patient (Sumner, 2011, pp 36–38). And lastly, this application of the Doctrine of Double Effect to end-of-life treatments wrongly presumes that death is always a harm to the patient (Sumner, 2011, p 58).

⁴⁹ There is debate in the literature on what constitutes an omission of an act, and whether withdrawing treatment constitutes an action causing death by interrupting ongoing treatment (Council of Canadian Academies, 2018, p 82; Sanchini et al, 2014, p 2).

The premise that there is exceptional ethical significance in an intentional request to die is grounded in an ethical doing/allowing distinction described in terms of the Doctrine of Double Effect. The following sections will examine two key factors in Sumner's critique of the Doctrine of Double Effect: that the effects have been consented to by the patient, and that death is wrongly presumed to be a harm to the patient. Both factors are significant to the view that mature minors cannot consent to MAiD because to them it is a decision of overwhelming magnitude. The personal and existential considerations in requesting death relate to developing judgments of the value of life and how such judgments are shaped by considerations of quality of life and suffering, as well as one's personal values.

6.5.1 Intrinsic Value of Life

The Doctrine of Double Effect portrays terminal sedation in terms of two effects: the relief of suffering, which is presumed to be "good," and the hastening of death, which is presumed to be "bad" (Sumner, 2011, p 58). According to the doctrine, the bad effect is acceptable only if it is the unintended side effect of intentionally bringing about the good effect. While he agrees that the relief of suffering has positive value, Sumner questions why death is presumed to carry negative value such that hastening death would be a bad thing. The presumption that the hastening of death is "bad" is grounded in a strong "sanctity of life" principle under a deontological ethic, which generally prohibits killing (Sumner, 2011, p 58). Sumner gives an analysis where he explains this rationale in terms of a deprivation account of the badness of death. This account maintains that dying is a harm because it deprives an individual of a life worth living (Sumner, 2011, p 58), and has been conceptualized in two ways.

One conception maintains that life is intrinsically valuable, and ascribes equal value to all persons (Liao and Chan, 2016, p 182). Where life is intrinsically valuable, the deprivation account of the badness of death maintains that death is extrinsically bad in that it deprives one of an intrinsic good (Sumner, 2011, p 58). Applied to MAiD, the intrinsic conception of the deprivation account of the badness of death argues that MAiD makes the assumption that "life filled with suffering is somehow not worth living" (Liao and Chan, 2016, p 182). Liao and Chan critique this assumption for failing to recognize that such life experiences are predicated on life itself and compelling children to prove through experiences that they deserve to live (2016, p 182). This reasoning has also been applied at the professional and institutional level. Brian S. Carter argues that the premise that life and health are intrinsically good in themselves, while suffering is intrinsically bad in itself has defined the goals of

medicine (2014, p 385). In particular, the goals of “healing and ‘relief of suffering” resist the notion of euthanasia (Carter, 2014, p 385).

An intrinsic conception of life also equates “a life worth living” with a worthy or valuable life, and has grounded claims for equal treatment in medicine regardless of life experience. This notion is connected with deontological accounts which assert that by ending one’s life through MAiD one violates a respect owed to everyone, including to oneself (Sumner, 2011, p 78). One deontological account (the natural law or Thomistic account) portrays that respect is owed to life, as it is an intrinsically fundamental aspect of human well-being which contributes to human fulfilment (Sumner, 2011, p 78). Under this account, any intentional taking of life is prohibited because it is a choice to destroy a fundamental good (Sumner, 2011, p 78). Further, destroying a fundamental good cannot be justified by another intrinsic good, for instance, relieving suffering (Sumner, 2011, p 79).

Under the other deontological account (Kantian), a duty to the self is grounded in the premise that all human beings should be respected as rational agents (Sumner, 2011, p 78). A duty to the self obligates each person not to hurt oneself or cause oneself injury (Sumner, 2011, p 82). Opponents of MAiD would argue that ending life is the greatest harm, and therefore that MAiD is impermissible by grossly violating a duty to the self. Respecting all human beings according to their rational nature motivates values of dignity, which has grounded arguments for the intrinsic value of life (Sumner, 2011, p 83). According to this view, where dignity conflicts with well-being, dignity takes unconditional precedence (Sumner, 2011, p 83). Thus, MAiD would be immoral in the case of a life which has lost all prudential value, as it disrespects the agent’s dignity as a person (Sumner, 2011, p 83).

Responding to the Thomistic account, Sumner challenges the notion that life itself is a fundamental value, arguing that life does not sufficiently contribute to well-being to be of intrinsic value, and would at most be of slight value if one does not benefit from other fundamental goods (2011, p 80). Moreover, Sumner identifies a gap in reasoning in the Kantian account, where the account does not explain how ending one’s life disrespects one’s dignity as a person. David Velleman compares euthanasia to the decision to sell oneself into slavery, both of which are objectionable because the person would demote his status from that of a free agent to that of a chattel (Sumner, 2011, p 83). Where Sumner recognizes the transition of dignity to indignity in the case of slavery, he challenges the applicability to end of life decisions (2011, p 83). Rather than a denigration of rational nature which disrespects oneself as a person, Sumner claims that the decision for MAiD is an expression of

autonomy and thus rational nature (2011, p 84). Moreover, Sumner questions the implication of Velleman's analogy that the condition of being dead is undignified (2011, p 83).

6.5.2 Instrumental Value of Life

Instead, Sumner presents an instrumental account of a "life worth living," where the life must be of sufficient benefit to the individual to be valuable to them. Rather than mattering in its own right, life matters in the sense that it is a necessary condition of everything that does matter (Sumner, 2011, p 80). Under this conception, whether death is a harm or benefit is dependent on the person's evaluation of the expected quality and duration of their continued life (Sumner, 2011, p 58). Sumner asserts that "death is not always harmful or something to be feared; it can be beneficial or something to be embraced" (Sumner, 2011, p 58). Sumner claims that death can be beneficial where suffering has reached the point where one perceives no value in their continued life (2011, p 58). This is principally because death would not deprive one of anything that would be intrinsically good (Sumner, 2011, p 80). The instrumental account is evoked by Jonathan Glover, who claims:

If life is worth preserving only because it is the vehicle for consciousness, and consciousness is of value only because it is necessary for something else, then that "something else" is the heart of this particular objection to killing. It is what is meant by a "life worth living" or a "worth-while life." (Sumner, 2011, p 80)

An instrumental account of a life worth living distinguishes between the notion of "having a life" as opposed to "being alive," where the latter is defined by a certain level of desirable experience and carries value. This distinction is likewise made between biological life and personal life. Biological life is defined in terms of the integrated functioning of an organism, where personal life requires the capacity of psychological states which constitute personhood (Sumner, 2011, p 79). Where biological life is still possible without consciousness or experience, consciousness is necessary for personal life and the subjective experiences which set life apart from death.

An instrumental account of a life worth living, where there are circumstances where death can be a good thing, undermines the central claim of the Doctrine of Double Effect. The Doctrine of Double Effect permits "bad" things for the sake of "good" ends, where the actor does not directly or indirectly intend the "bad" thing. If MAiD is sought based on a poor life experience with no instrumental value, then intentionally causing death by practising MAiD does not violate the Doctrine of Double Effect, because death in such cases can be a "good" thing. Circumstances where life has no instrumental value, where one's life experience is poor and the person's life is "meaningless in and of

itself” (Liao and Chan, 2016, p 182), may also be circumstances where MAiD is a relevant option: where one has a grievous and irremediable medical condition.

A concern with this articulation of an interests-based account of the value of life is that it is unclear what interests must be met to define a “life worth living,” and whether there can be reasonable disagreement between individuals regarding whether one’s life is worth living. Could this leave patients vulnerable to the external judgments of others regarding the value of their life? Sumner resolves these concerns by building an account which defines a “life worth living” in terms of factors based in welfare and self-determination. Sumner builds on Ronald Dworkin’s account of experiential and critical interests. Under this account, pleasure, and enjoyment (i.e., “good”), and the avoidance of pain and suffering (i.e., “bad”), further one’s experiential interests (Sumner, 2011, p 120). Meanwhile, the pursuit and achievement of life goals and ambitions (i.e., good) and the avoidance of disappointments and frustrations (i.e., bad), based on the formation of one’s values, further one’s critical interests (Sumner, 2011, p 120). A sentient infant has basic experiential interests, including food, warmth, rest, and the avoidance of pain (Sumner, 2011, p 120). As a child matures, their experiential interests become more complex, and they develop critical interests (Sumner, 2011, p 120). This means that a mature child’s interests are understood both in terms of “good” experiences, and the achievement of life goals which are based on their values. A proportional balance of experiential and critical interests where the good outweighs the bad constitutes a life worth living, where death deprives one of a worthwhile life (Sumner, 2011, 120). Where critical interests conflict with experiential interests, Dworkin argues that critical interests should take precedence – a claim which is least controversial where the patient is capable (Sumner, 2011, p 109).

Meanwhile, a proportional balance where the experiential and critical bad far outweighs the experiential and critical good would constitute a life not worth living, where death would not deprive one of a worthwhile life. Sumner also asserts that a life which contains no bad but also no present or future good (e.g., where recovery of consciousness is impossible) is subjectively indistinguishable from being dead (2011, p 120). In such cases, it is not against a child’s interests to die, and their interests are not always best served by continued life. While ending a life may preclude the possibility of an unexpected positive outcome, it may be warranted.

Returning to the argument from weightiness, it is significant to note that Dworkin’s critical interests were initially applied to the question of advance directives. In this context, individuals are presumed to have long been previously capable and have critical interests that can be evaluated in

terms of long-standing life goals grounded in personal values held over time. Mature minors are capable, and in evaluating a life worth living in terms of the proportional balance of interests, their critical interests take precedence. Under this lens, the argument from weightiness expresses concern for the mature minor's ability to formulate values, ambitions, and life goals, and applies these to a decision about the value of life. Where mature minors are capable of weighing the clinical benefits and harms of MAiD, proponents of the argument from weightiness claim that "most young minors do not have particular life-ends" and that their "sense of purpose and goal in life is limited, and ... unstable, subject to change as they acquire new experiences" (Cohen-Almagor, 2018, p 238). Without life ends, the argument from weightiness argues that mature minors are incapable of evaluating whether these harms and benefits lend to the achievement of a valuable life or take away from the achievement of a valuable life. Moreover, this evaluative ability cannot be developed without adequate life experience, which is needed to inform these values, ambitions, and life goals.

6.6 Applying an Instrumental Value of Life to the Argument from Weightiness

Under Sumner’s conception of an instrumental value of life, whether death is harmful or beneficial is subject to personal evaluation, taking into consideration the expected quality and duration of one’s continued life (Sumner, 2011, p 58). Factoring in the expected duration of one’s life has a bearing on the application of one’s critical interests – as values, life goals, and ambitions are responsive to expectations about the future. This could mean that there is more at stake in some decisions to refuse life-saving treatment, where treatment could provide a lengthy future, than there is in the decision to receive MAiD, where one’s natural death is reasonably foreseeable. If mature minors are permitted to refuse life-sustaining treatment (a more weighty decision), than why are minors prohibited from requesting MAiD (a less weighty decision)?

The impact of a future in conceptualizing a child’s interests has been used in comparing “life and death” decisions with other kinds of decisions. Decisions safeguarded by age limits which are not a matter of “life and death,” such as buying alcohol, driving or voting, interpret a child’s interests in terms of “protecting a child’s life and prioritizing their future” (Raus, 2016, p 310). Yet in the Belgian context, where a minor’s death must result in a short period of time to be eligible for euthanasia (2016, p 307), Raus observes that seriously ill minors do not necessarily expect a lengthy future (2016, p 310). This factors into interpreting the child’s best interests – where there is no future to safeguard a child from, and where having a peaceful death is interpreted to further their interests (Raus, 2016, p 310). The impact of a future on age distinctions is also invoked by the Canadian Coalition for the Rights of Children, who argue that unlike other decisions which can be deferred to adulthood, MAiD cannot be deferred⁵⁰ and an age distinction forever denies the treatment to children (Council of Canadian Academies, 2018, p 121).

A similar analysis can be made concerning “life and death” decisions by comparing refusal of life-sustaining treatment and MAiD. Consider the decision to refuse life-sustaining treatment outlined in *AC v. Manitoba* (2009). At 14 years of age, AC suffered an episode of lower gastrointestinal bleeding as a result of Crohn’s disease, for which she required a blood transfusion to recover (*AC v. Manitoba*, 2009, par. 5–7). Without the treatment, AC risked serious damage and death (*AC v. Manitoba*, 2009, par. 12). In particular, among other serious and potentially fatal complications, she risked serious

⁵⁰ This argument was made in the context of Bill C-14, under which a person’s natural death must be reasonably foreseeable to be found eligible. Since the Council of Canadian Academies published their report, Bill C-7 expanding eligibility to persons whose natural deaths are not reasonably foreseeable. Implications of Bill C-7 will be discussed further in Chapter 7 of this work.

oxygen deprivation, organ failure, and seizures (AC v. Manitoba, 2009, par 11). Yet due to religious reasons as a Jehovah's Witness, AC refused the treatment, and months prior had completed an advance directive with written instructions not to receive a blood transfusion under any circumstances (AC v. Manitoba, 2009, par. 5–7).

In this case, the decision AC faced was a dichotomy between the choice to live and the choice to undertake a significant risk of death – a true matter of life and death. AC's refusal of treatment presented a minimal window of opportunity to reverse or mitigate the decision.⁵¹ With treatment, AC would likely recover⁵² and therefore would have the option of a lengthy life and future – one which should be prioritized through the safeguarding which protects children in contexts of buying alcohol, driving, or voting. By refusing treatment, AC was choosing to risk ending her life where death was preventable, and was rejecting her prospects of a lengthy life and future. This additional consideration of rejecting a lengthy life and future arguably makes AC's refusal of treatment the weightiest decision possible. Yet AC was deemed able to make this choice. A psychiatric assessment found that she understood the nature of her illness, her treatments, why a blood transfusion may be recommended, and the consequences of refusing to have a transfusion (AC v. Manitoba, 2009, par. 6 and 181).

Meanwhile, a decision for MAiD is comparatively less weighty as it does not entail rejecting a lengthy life and future – the life goals and values mean to develop over a life cycle are unlikely to relevantly apply to the decision. Instead one's expected future is short, and one faces irreversible decline and intolerable suffering: a future where one's critical or experiential interests are best fulfilled by a good death. MAiD may fulfill such interests by enabling control over how one dies.

Moreover, AC's decision to refuse life-sustaining treatment was made almost entirely on the basis of her critical interests – demonstrating that mature minors are already permitted to make sophisticated existential and personal decisions. Rather than reasons based on a grievous and irremediable medical condition, AC's decision was motivated by religious belief. As a Jehovah's

⁵¹ AC's condition was sufficiently emergent that she was treated against her will within the same day (Day, 2009, pp 672–673). AC refused a blood transfusion on the morning of April 16 (AC v. Manitoba, 2009, par. 7). An emergency application for a court order to treat AC against her will was granted, and about six hours later, AC was given three units of blood (AC v. Manitoba, 2009, par. 12–13). The treatments were successful and AC recovered. The application was withdrawn on May 1 (AC v. Manitoba, 2009, par. 13).

⁵² In his dissenting opinion, Justice Binnie recognized that the decision to accept a blood transfusion was “not without risk,” referencing an exhaustive review of medical literature by a panel of experts which shows an “association between red blood cell transfusions and higher rates of complications such as heart attack, stroke, lung injury, infection and kidney failure and death” (AC v. Manitoba 2009, par 217).

Witness who was voluntarily baptized two years prior, AC believed that blood represents life and is a gift from God (AC v. Manitoba, 2009, par. 214). Further, Jehovah's Witnesses believe that respect for this gift from God, as well as personal responsibility "to maintain a clean standing" (AC v. Manitoba, 2009, par. 181) before God requires abstaining from accepting blood to sustain life (AC v. Manitoba, 2009, par. 213). Due to these beliefs, which were deemed to be sincere and fundamental to AC's religion (AC v. Manitoba, 2009, par. 214), AC valued her relationship with God and developed life goals of ensuring spiritual life – where achieving these life goals entailed following the spiritual tenets of her faith, and breaking these tenets would result in disappointment and frustration. The Supreme Court of Canada recognized this application of critical interests in their judgment. Asking a minor to question their faith, to understand ethical arguments which relate to their decision, or to comprehend the pain, fear, and distress associated with dying could risk holding minors to standards that many adults could not meet (Council of Canadian Academies, 2018, p 82).⁵³

Where the decision to refuse life-sustaining treatment is more weighty and can be made completely on the basis of critical interests, this bears on arguments for consistency. Legal precedent indicates that the courts have "have accepted the legal option of mentally competent free individuals to risk preventable death rather than be compelled to live under conditions they find objectionable" (AC v. Manitoba, 2009, par. 201). Further, some "decisions by mature minors to refuse life-sustaining treatment have been upheld by the courts, particularly when the refusal was grounded on religious belief" (Gilmour, 2011, p 392). These permissions should likewise warrant mature minors to make decisions based on their critical interests where death is not preventable.

6.7 Conclusion

This chapter considered a novel conception of an ethical distinction between MAiD and other end-of-life treatments, including the refusal of life-sustaining treatment, pain management, and palliative sedation. Rather than distinguishing the nature of the treatments themselves (often in terms of ethical implications for the physician), the argument distinguishes between the natures of the decisions from the perspective of the patient. Under this conception, MAiD is too weighty, requiring sophisticated judgments about the value of life that mature minors are unable to make. Yet such sophisticated

⁵³ The Council of Canadian Academies references Ferguson L. Uncertainty and Indecision in the Legal Regulation of Children: The Albertan Experience. "Canadian Journal of Family Law". 2007, 23(2).

judgments are evidenced in mature minor refusal of life-sustaining treatment, where some refusals are based entirely upon religious values and beliefs.

Moreover, refusing life-sustaining treatment is arguably more weighty a decision than the choice to receive MAiD. Mature minors are permitted to refuse life-sustaining treatment under the Canadian legal framework, revealing that some minors have sophisticated judgment, as minors can choose to die when their death is preventable. If mature minors have the sophisticated judgment to refuse life-sustaining treatment and refusing life-sustaining treatment is a more weighty decision than MAiD, then it follows that mature minors also have the sophisticated judgment required to choose how they die where death is not preventable. These insights challenge an ethical distinction between MAiD and other end-of-life treatments, and support the argument that mature minors should be permitted to access MAiD, as prohibiting MAiD for mature minors treats them inconsistently under the law.

Accepting the ethical argument that refusing life-sustaining treatment requires a higher threshold of judgment than that required to choose MAiD, opponents of MAiD may still argue that the appropriate response is not to strike the 18-year-old age restriction from the Criminal Code, but rather to create a mechanism through the courts to allow mature minor access to MAiD on an exceptional basis, such as a free-standing constitutional exemption. One justification is that, while a less weighty judgment than withdrawing or refusing life-sustaining treatment, MAiD may still be compared with decisions to vote, marry, drink alcohol and smoke tobacco, and to drop out of school – asking why MAiD is permitted as a more weighty decision.

Yet MAiD is distinguished from these choices, as it is an end-of-life decision which cannot be deferred to adulthood (Council of Canadian Academies, 2018, p 121). Where an age distinction merely defers a decision in most contexts, it forever denies the decision to children in the context of MAiD (Council of Canadian Academies, 2018, p 121). Further, MAiD, like the withdrawal and withholding of life-sustaining treatment, is a medical decision. Chapter 4 discussed the issue of whether an age distinction in *AC v. Manitoba* (2009) should be upheld as a “common and necessary way to order society” (par. 110). The Supreme Court of Canada distinguished medical decision-making from other contexts. In cases of medical decision-making, age distinctions are an indicator to shift presumptions of capacity: individuals below the age of consent are presumed to lack capacity unless proven otherwise, while individuals above the age of consent are presumed to be capable unless proven otherwise (*AC v. Manitoba*, 2009, par. 111). Under this system, mature minors (adolescents who rebut their presumption of incapacity) can consent to refuse life-sustaining

treatment. As a medical decision, MAiD likewise fits into this context of imposing age distinctions based on shifting presumptions of capacity.

Another justification for an argument for free constitutional exemption acknowledges that the numbers of mature minors who qualify for MAiD is likely to be small, and emphasizes that the safeguards in the law are effective for the vast majority of children and adolescents, arguing that there ought not to be a blunt overhaul of the law on the basis of rare potential infringements of the Charter rights of minors. Responding to this argument, it is important to note that s. 7 analysis of the principles of fundamental justice is qualitative rather than quantitative. This means that an arbitrary, overbroad, or grossly disproportionate impact on one person is sufficient to establish that the law violates s.7 (Canada AG v. Bedford, 2013, par. 123; Department of Justice, 2021, web). Moreover, Chapter 1 summarized the Supreme Court's judgment on this question in the adult context in *Carter v. Canada* (2015). Addressing the prospect of issuing a free-standing constitutional exception as a remedy for the law's s. 7 Charter violation, the Supreme Court argued that a mechanism of constitutional exemption for MAiD would be a case of improper judicial discretion which may retain a law which risks unconstitutional treatment of Canadians (*Carter v. Canada*, 2015, par. 125). Based on this reasoning, if a mature minor brought a successful constitutional challenge to the Supreme Court, the remedy would most likely lie in parliamentary reform of the law rather than a constitutional exemption.

Chapter 7

Conclusion and Further Research

7.1 Summary

7.1.1 Chapter 1: Introduction and Legal Background

Chapter 1 gave an overview of the legal decisions and legislative changes which decriminalized MAiD in Canada, along with actual and potential challenges to eligibility criteria in the wake of decriminalization. It began with two landmark Supreme Court of Canada cases: *Rodriguez v. BC* (1993), and *Carter v. Canada* (2015). The Supreme Court of Canada in *Carter* framed MAiD as a tension of values between autonomy and dignity on the one hand, and sanctity of life and protecting the vulnerable on the other, and found that the criminal prohibition of MAiD violated s. 7 rights to life, liberty, and security of the person by forcing some individuals to take their lives prematurely, denying them the right to autonomous decisions, and forcing other individuals to endure intolerable suffering. Further, through strong safeguards and oversights, the Court ruled that a permissive regime would be able to protect the vulnerable from abuse and error.

The Government of Canada responded to the *Carter* decision with Bill C-14, which legalized MAiD and, among other criteria, set eligibility at 18 years of age. Bill C-14 outlined three cases requiring further independent review: mature minors, advance requests, and mental illness as a sole underlying condition. Each case presents challenges related to decision-making capacity and vulnerability despite existing safeguards. With respect to mature minors, there are challenges reconciling the age distinction made in Bill C-14 with the legal regime governing most adolescent health care decisions in Canada. Likewise, similarly to the adult context, concerns centred around autonomy in balancing self-determination and welfare (protecting vulnerability). Concerns for minors' vulnerability relate to the risk that they may lack the requisite decision-making capacity to consent to MAiD. Yet it is recognized that children can experience a similar degree of suffering to adults, and have developing decision-making capacity.

7.1.2 Chapter 2: An Analysis of Mature Minor Autonomy and Vulnerability

Chapter 2 gave an analysis of the ethical values of autonomy and welfare (in terms of vulnerability) in the context of MAiD for mature minors. The chapter characterizes autonomy (though self-determination) in terms of authority to make decisions on matters affecting one's own interests.

Under this conception, decision-making authority is conceived as a straightforward function of one's agency. The chapter then reviews the child development literature, yielding four principle factors related to agency and the ability to make healthcare decisions: developing capacity, the ability to hold goals and commitments, strength of will to act in line with their own values and wishes, and personal experience of illness. From this analysis, the work finds a general indication in child development literature that some adolescents over the age of 14 may have sufficient capability, ability, and experience to consent to MAiD. Such abilities may create duties to respect their autonomy and dignity. Yet these obligations may also be outweighed by welfare considerations. Some child development experts argue that, even where capable, minors may possess insufficient inhibition, emotional and behavioural self-regulation, and psychosocial competence to consent to MAiD. Additional vulnerability concerns to protect children's welfare by limiting their decision-making authority may be motivated by duties of beneficence, promoting a child's open future, and parental authority and interests.

7.1.3 Chapter 3: The Legal Landscape

Similar conceptual tensions between welfare and self-determination are also present in the legal regime regulating child and adolescent health care decision-making. The values of welfare and self-determination are expressed through provincial legislation. Throughout Canada there is variability, yet most Canadian provinces do not specify an age of consent (exceptions are 14 in Quebec and 16 in New Brunswick). In Ontario, capable children have the authority to make their own health care decisions. Yet mature minors cannot make decisions on behalf of others, and are also limited with respect to certain aspects of health care decision-making. Further, children's welfare is upheld through child protection legislation, which may become engaged in cases of refusing consent to necessary treatment.

Similarly, the courts have weighed the competing values of welfare and self-determination with respect to adolescent health care decision-making. The mature minor principle, which grants mature minors decision-making authority with respect to treatment, is a product of common-law jurisprudence, sourced in *Gillick v. West Norfolk and Wisbech Area Health Authority* (1985). This decision ruled that capable adolescents under 16 can consent to medical treatment as effectively as an adult and cannot be overruled by a parent. Yet decisions in *Re R (A Minor) (Wardship: Consent to Treatment)* (1991), and *Re W (A Minor) (Medical Treatment)* (1992) conflict with that of *Gillick*, limiting mature minor authority and asserting state authority in limiting mature minor decisions to

protect their welfare under *parens patriae* jurisdiction. Recent cases in the Canadian courts, however, have upheld mature minor authority, even in cases of refusal of life-sustaining treatment. In *AC v. Manitoba* (2009), the SCC rejected interpretations of child protection legislation which enable child protection authorities to overrule the authority of mature minors refusing necessary treatment. Meanwhile, conceptions of a child in need of protection and the “best interests of the child” were interpreted to recognize Aboriginal and treaty rights to traditional medicine and health care practices in *Hamilton Health Sciences Corp. v. D.H.* (2014).

7.1.4 Chapter 4: Age Distinction in Canada’s Bill C-14: Necessary or Discriminatory?

Taking into account the conceptual and legal tensions regarding a mature minor’s authority to make health care decisions outlined in Chapters 2 and 3, Chapter 4 analyzed a potential outcome of a mature minor challenge to the Criminal Code. Applying the rulings in *Carter v. Canada* (2012 and 2015), *Truchon c. Procureur général du Canada* (2019), and *AC v. Manitoba* (2009), the analysis argued that a mature minor challenge to Bill C-14 would have a strong claim, on the basis of violations to s. 7 and s. 15 of the Charter.

A s. 7 challenge was explored under the argument that the law may have the effect of shortening life, and may interfere with mature minor autonomy by impeding liberty and forcing intolerable suffering. With respect to the right to life, it is conceivable and compelling that the reasoning used in *Carter* that prohibiting MAiD infringes on the right to life applies to the mature minor context. Rights to liberty are also infringed, based on the reasoning used in *AC*, *Carter*, and *Truchon* that the law interferes with individuals’ ability to make fundamental personal decisions about their bodily integrity and medical care. Reasoning from *Carter* and *Truchon* supports the conclusion that security of the person would be infringed, as the law forces individuals to endure intolerable suffering. Based on *AC*, any s. 7 infringement is unlikely to be in accordance with the principles of fundamental justice as a result of being arbitrary, due to the assumption that a mature minor cannot have capacity to make medical treatment decisions.

The chapter then turned to analyzing the prospect of a s. 15 challenge to Bill C-14’s age restrictions on the grounds that restricting mature minors from MAiD is a case of age discrimination. In particular, it considers questions of whether the law disadvantages mature minors, or whether the purpose or effect of the law is ameliorative. Underlying this analysis are two tensions: (1) whether differential treatment on the basis of age is justified as a common and necessary way to order society, and (2) whether the law serves to restrict or to protect mature minor interests. The analysis ultimately

found a strong case that prohibiting MAiD for mature minors on the basis of their age is unjustifiable, as it disadvantages them through inaccurate and harmful stereotyping about their ability. Yet the analysis of *AC v. Manitoba* revealed that in the context of medical decision-making, age distinctions may be used as an indicator to shift presumptions of capacity. Moreover, while it is unclear that the question of an ameliorative purpose is relevant to the case, the law limits the interests of mature minors by having the invidious effect based on the paternalism of imposing suffering upon capable minors. Analysis of s. 1 was framed in terms of whether a more permissive regime could address risks to mature minors as vulnerable persons. By applying the Supreme Court of Canada's reasoning in *AC v. Manitoba* (2009) to the issues, this chapter found that eligibility calibrated according to maturity rather than age would adequately address any risks of a vulnerable person being induced to commit suicide in a time of weakness.

7.1.5 Chapter 5: Best Interests and Welfare at the End of Life

Chapter 3 established that in cases where a parent refuses necessary treatment, child protection legislation authorizes the transfer of care to consent on the child's behalf; yet it raised the possibility that the court's *parens patriae* jurisdiction could be invoked to override a capable minor's wishes. Given this context, the impact of child welfare legislation is unclear if eligibility is extended to mature minors. Chapter 5 built on the argument made in Chapter 4 that prohibiting mature minors from accessing MAiD is invidious rather than ameliorative, considering this question in terms of the concept of the "best interests of the child." In particular, the chapter considered whether the finality and irreversibility of MAiD requires welfare considerations to take precedence over self-determination.

The factors relevant to making a decision in accordance with a patient's best interests include known values and beliefs held while capable, expressed wishes regarding treatment, and a number of issues surrounding the patient's well-being. As this chapter sought to investigate conceptions of welfare at the end of life, end-of-life decisions on behalf of infants became the focus since this is the cohort where judgments of best interests are interpreted completely on the basis of welfare considerations. This chapter analyzed the literature on clinical welfare judgments regarding paediatric end-of-life decisions, along with insights from the Ontario Consent and Capacity Board.

Welfare considerations in determining a child's best interests include whether the treatment is likely to improve the patient's condition or well-being; whether the treatment is likely to prevent, or reduce the extent to which the incapable person's condition or well-being is deteriorating; the

likelihood of the patient's condition improving, remaining the same, or deteriorating without the treatment; the proportionality of expected benefit to risk of harm of the treatment; and whether a less restrictive/intrusive treatment would be as beneficial as the proposed treatment. The analysis found that welfare in end-of-life decisions is principally a clinical judgment. Clinical judgments of futility (where interventions are not recommended because of unlikely survival or unacceptable outcomes) illustrate that prolonging life may inhibit rather than promote children's welfare, and that quality of life and suffering are welfare considerations in end-of-life decisions. These insights are also found in CCB judgments on end-of-life decisions, along with the insight that judgments of welfare include well-being, which is more broad than the status of one's physical illness, and take into consideration less tangible considerations such as dignity and humanity.

7.1.6 Chapter 6: MAiD and Refusal of Life-Sustaining Treatment: Is There an Ethical Distinction?

Chapter 6 considered whether mature minors should be ineligible for MAiD due to a fundamental ethical distinction between MAiD and other end-of-life decisions, including the decision to refuse life-sustaining treatment. The chapter compared MAiD with other end-of-life decisions, making a distinction based in the argument from weightiness. The argument claimed that MAiD is the most "weighty" decision one can make, and that it is inconsistent to allow minors to make this life-and-death decision while being unable to make "less serious" decisions. Two factors were then identified to challenge the argument from weightiness:

- (1) That life is not intrinsically valuable, and that the determination of whether death is a harm or benefit is dependent on the person's evaluation of the expected quality and duration of their continued life.
- (2) That life has experiential and critical value, and to intentionally end one's life is not merely an "objective" clinical matter, but also involves careful considerations of personal "subjective" value.

Based on these factors, this chapter made the argument that the decision AC made to refuse life-sustaining treatment was a choice to risk ending her life where death was preventable, a far weightier decision than the choice to receive MAiD, a choice of how one dies where death is unavoidable. Yet AC was deemed able to make this choice. Moreover, as a decision made on the basis of religious belief, AC was permitted to make a sophisticated existential and personal decision. Thus, a distinction

permitting a minor to refuse life-sustaining treatment while refusing to allow minors to consent to MAiD treats minors inconsistently.

7.2 Analysis

Through analyzing legal and ethical obligations, welfare considerations, and a comparison of MAiD to other end of life decisions, this dissertation finds three strong ethical arguments that minors ought to be eligible for MAiD where they meet the other criteria outlined under Bill C-14. The first argument is that mature minors are capable of making autonomous healthcare decisions, and so the prohibition violates their s. 7 rights and their rights to self-determination, for reasons similar to those outlined for adults in the Carter decision. The second argument is that excluding mature minors is an unjustifiable act of age discrimination under s. 15 of the Charter, because just like adults, mature minors ought to be given the opportunity to prove their capacity. The analysis of legal and ethical duties to mature minors under statutory and common law in Chapters 3 and 4 of this work reveal that mature minors have strong claims to access MAiD under the legal regime guiding child and adolescent health care decision-making in Canada. In Ontario and the majority of Canadian provinces, capable children have authority with respect to their own health care decisions. This authority is based on the mature minor principle: that capable adolescents under the age of 16 can consent to medical treatment as effectively as an adult and cannot be overruled by a parent. This authority has been upheld in the courts – including in cases where an adolescent chooses to die by refusing life-sustaining treatment. There is a risk that prohibiting MAiD for mature minors has the effect of shortening life, and that minors suffer similar deprivations to their liberty and experience forced intolerable suffering as adults once had before MAiD was decriminalized in Canada. Given these effects of the provisions, the law disadvantages youth by propagating harmful stereotypes on ability as a function of one's age.

Yet there are stronger legal and ethical duties to protect children's interests than those of adults, and we organize society such that children are prohibited from making many decisions to protect their welfare. Examples include voting and performing other duties of citizenship; joining military service; consenting to sexual intercourse, getting married, and raising children; purchasing alcohol or tobacco; and dropping out of school. Minors are also held to a different standard of accountability for their decisions in the criminal justice system, and receive different sentencing than adults. In the context of health care decisions, the degree of state authority to limiting mature minor decisions to protect their welfare under *parens patriae* jurisdiction remains unclear. So it could be that the legal prohibition of mature minor access to MAiD is required because of the special moral and legal obligations we have to protect the welfare of minors.

The third argument is that prohibiting mature minors from accessing MAiD does not protect their welfare, and may actually be harmful. Chapter 4 considered the question of whether excluding mature minors from eligibility for MAiD is ameliorative in its purpose or effects. The analysis found that the law limits the interests of mature minors by having the invidious effect based on the paternalism of imposing suffering upon capable minors. Further, Chapter 5 questioned the premise that a decision to shorten life is welfare-limiting – finding that in some situations (for instance in cases of futility) the benefits of relief of suffering, dignity, and quality of life can outweigh the harm of shortening life. In particular, the analysis reframes questions of welfare from a matter of whether one dies to a matter of when and how, and what happens to a person until they die. Where a request for MAiD is motivated by severe pain and suffering, a low quality of life, and an unwillingness to endure continued indignities, it may be motivated by welfare considerations. The analysis demonstrated that a decision to receive MAiD may be motivated by welfare considerations where it is motivated by severe pain and suffering, a low quality of life, and an unwillingness to endure continued indignities. Prohibiting mature minors from accessing MAiD therefore cannot be justified by an ethical or legal obligation to protect the welfare of minors; in fact, any such obligation speaks in favour of permitting mature minor access to MAiD.

Finally, this dissertation comments on the inconsistency created under the law, which rightly permits mature minors to make far-reaching medical decisions which affect the timing of one's death, such as refusing life-sustaining treatment, yet prohibits them from consenting to MAiD. The third argument in favour of extending MAiD access to mature minors is that there is no conceptual ethical distinction between MAiD and other end-of-life decisions. In particular, Chapter 6 rejects the notion that a decision to receive MAiD requires a higher degree of capability and sophisticated judgment than the decision to refuse life-sustaining treatment. Analysis revealed that refusing life-sustaining treatment, a choice to die where one could otherwise live, is a weightier decision than the decision to receive MAiD, a choice of how one dies where death is unavoidable. The analysis also argues that the expected duration of one's life has a bearing on the application of one's critical interests, since there is more at stake in decisions where there is an option for a lengthy future than in circumstances where one's natural death is reasonably foreseeable. By this reasoning, the decision to refuse treatment on the basis of religious belief requires a higher degree of capability and sophistication than the decision to receive MAiD.

7.3 Further Research

Minors ought to be eligible for MAiD where they meet the other criteria outlined under Bill C-14 based on three arguments: mature minors are capable of making autonomous healthcare decisions and thus exclusion from eligibility engages their s. 7 rights; excluding mature minors is an unjustifiable act of age discrimination under s. 15 of the Charter; and prohibiting mature minors from accessing MAiD does not always protect their welfare and may actually be harmful. Yet this argument assumes a request from a capable adolescent who otherwise meets all eligibility criteria under Bill C-14 and whose parents are fully supportive of the MAiD request. This section considers two factors in order to explore more complex cases and issues beyond the scope of the project, which are worthwhile subjects for future research.

7.3.1 The Role of the Parent

Chapter 2 of this dissertation considered mature minor autonomy in terms of the child's authority as a function of their agency and ability. Yet the chapter considered whether parental rights and authority might justify parents intervening in their child's decision. Exploring this question further, particularly in cases where parents are opposed to their child's request for MAiD, is an area of further research.

In particular, Chapter 2 considered the idea that parental authority may be rooted in their interests in raising their child according to their own vision of the good life. The Council of Canadian Academies report considered the ethical viewpoint that the decision-making authority of minors is linked to the responsibilities and interests of their family, where parental responsibilities to care for and protect their children still remain (CCA, 2018, p 77). While the Expert Panel reiterated the position statement from the Canadian Paediatric Society that while the "impact on the family ... must be considered in end-of-life decision-making, these interests should not be allowed to override those of the child or adolescent" (CCA, 2018, 107).

Yet the Society statement also articulates a commitment to the "best interests of the child" (CCA, 2018, 107). Under the UN Convention on the Rights of the Child, parents have responsibilities to the best interests of the child, as articulated in Article 18:

Parents or, as the case may be, legal guardians, have the primary responsibility for the upbringing and development of the child. The best interests of the child will be their basic concern.

Articles 3 and 18 of the CRC guide the operationalization of “best interests” in paediatric medicine. Decisions for paediatric patients, while motivated by considerations of well-being and self-determination, may be influenced by parental values. Further, parents have a key role in supporting a capable adolescent at the end of life. Taking into consideration the complexity of their decision, a mature minor experiencing serious illness who has decision-making authority may wish for their parents to be actively involved in decision-making.

Furthermore, these questions are also relevant to the legal regimes in Belgium and the Netherlands, jurisdictions where minors are already permitted access to euthanasia. In Belgium, legal representatives (often the parents) must give formally documented consent (Raus, 2016, p 311). Meanwhile in the Netherlands, minors requesting euthanasia require consent of a parent or guardian from the ages of 12 to 16, and parental involvement from at ages 16 and 17 (Government of the Netherlands, NDA, web). Recently, the Dutch government has approved plans to allow euthanasia for terminally ill children aged between 1 and 12 with parental consent, expected to be implemented within the next few months (BBC, 2020, web). Yet some legislators and experts question what ought to happen when parents disagree, and interpret the requirement for parental consent in terms of guardianship, calling into question the claims that some minors are fully competent to request euthanasia (Raus, 2016, p 311).

7.3.2 Natural Death Is Not Reasonably Foreseeable; Mental Illness as a Sole Underlying Condition

Chapter 1 discussed *Truchon c. Procureur général du Canada* (2019), where the Quebec Superior Court decision which found that the eligibility criterion of a reasonably foreseeable natural death was unconstitutional, as it infringed on the applicants’ ss. 7 and 15 Charter rights. The federal government and the provincial government of Quebec chose not to appeal the decision, and Bill C-7 later received royal assent on March 17th, 2021. Bill C-7 creates two streams of eligibility safeguards: these are eased in cases where a natural death is reasonably foreseeable, and are enhanced where a natural death has not become reasonably foreseeable. Further, where a natural death has not become reasonably foreseeable, a greater emphasis is placed upon medical expertise in the patient’s underlying condition.

Removing the requirement for a reasonable foreseeable natural death is predicted to expand eligibility for MAiD, where patients who were formerly ineligible may now qualify. Individuals who may qualify for MAiD under Bill C-7 include patients with psychiatric disorders, chronic pain, mind-

body conditions, spinal cord injuries, acquired brain injuries, and some forms of dementia.⁵⁴ These anticipated changes have raised concerns regarding increased complexity in implementing legal safeguards. In particular, risks relating to complex and diverse sources of suffering and vulnerability, along with uncertainties in clinical judgment, may raise conflicting values with respect to MAiD requests.

It is unclear how mature minors would fit into this new legal regime under Bill C-7, particularly if they were to qualify in circumstances where their natural death has not become reasonably foreseeable or where mental illness is a sole underlying condition. There is hesitancy in the mature minor debate based on fears that competent minors who are not imminently dying will seek MAiD and will die when their death is preventable. Analysis in Chapter 6 made the argument that the decision to receive MAiD required less sophisticated judgment than a case of refusing life-saving treatment, based on the premise that one has a reasonably foreseeable natural death. Where a natural death is not reasonably foreseeable, the decision for MAiD becomes more complex, where a child could risk needlessly giving up a long life, hopes that their condition will remediate, or the possibility that they will adjust to their situation in time (Raus, 2016, p 309). Similarly to the adult context, mature minors requests for MAiD could raise the possibility of high-risk cases, and could potentially involve challenging requests from “love-sick minors or confused teenagers” (Raus, 2016, p 309).

⁵⁴ At the time the law received royal assent, Bill C-7 excluded patients with mental health as a sole underlying condition from eligibility for MAiD under a sunset clause which will come into effect on March 17, 2023.

Bibliography

1. Bill C-14 *An Act to amend the Criminal Code and to make related amendments to other Acts (medical assistance in dying)*, First Session, Forty-second Parliament, 64-65 Elizabeth II, 2015-2016. Available from: <https://www.parl.ca/DocumentViewer/en/42-1/bill/C-14/royal-assent>
2. Rodriguez v. British Columbia (Attorney General), [1993] 3 S.C.R. 519. Available from: <https://scc-csc.lexum.com/scc-csc/scc-csc/en/item/1054/index.do>
3. Canadian Charter of Rights and Freedoms, s 7, Part 1 of the Constitution Act, 1982, being Schedule B to the Canada Act 1982 (UK), 1982, c 11. Available from: <https://laws-lois.justice.gc.ca/eng/const/FullText.html>
4. Carter v. Canada (Attorney General), 2012 BCSC 1587. Available from: <https://www.bccourts.ca/jdb-txt/SC/12/15/2012BCSC1587.htm>
5. Carter v. Canada (Attorney General), 2015 SCC 5, [2015] 1 S.C.R. 331. Available from: <https://scc-csc.lexum.com/scc-csc/scc-csc/en/item/14637/index.do>
6. Government of Canada. Section 7 – Life, liberty, and security of the person. Canada’s system of justice. Department of Justice. 2021. Available from: <https://www.justice.gc.ca/eng/csjsjc/rfc-dlc/ccrf-ccdl/check/art7.html>
7. Canada (Attorney General) v. Bedford, 2013 SCC 72, [2013] 3 S.C.R. 1101. Available from: <https://scc-csc.lexum.com/scc-csc/scc-csc/en/item/13389/index.do>
8. R. v. Demers, [2004] 2 S.C.R. 489, 2004 SCC 46. Available from: <https://scc-csc.lexum.com/scc-csc/scc-csc/en/item/2160/index.do>
9. Downie J, Bern S. Rodriguez redux. *Health Law*. 2008; 16:27. Available from: <https://ssrn.com/abstract=2081875>
10. Schuklenk U, Van Delden JJM, Downie J, McLean S, Upshur R, Weinstock D. Royal Society of Canada expert panel: end-of-life decision making. Royal Society of Canada; 2011. Available from: https://rsc-src.ca/sites/default/files/RSCEndofLifeReport2011_EN_Formatted_FINAL.pdf
11. Bateman T, Hiebert J, Knopff R, Russell P. *The court and the Charter: leading cases*. 2nd ed. Toronto: Emond Montgomery Publications Limited; 2017.

12. McLachlin B. The Charter 25 years later: the good, the bad, and the challenges. Osgoode Hall Law Journal. 2007;45:2. Available from: <https://digitalcommons.osgoode.yorku.ca/cgi/viewcontent.cgi?referer=https://www.google.com/&httpsredir=1&article=1245&context=ohlj>
13. R. v. Ferguson, [2008] 1 S.C.R. 96, 2008 SCC 6. Available from: <https://scc-csc.lexum.com/scc-csc/scc-csc/en/item/2406/index.do>
14. Downie J, Chandler JA. Interpreting Canada's medical assistance in dying legislation. IRPP Report. 2018. Available from: <https://irpp.org/wp-content/uploads/2018/03/Interpreting-Canadas-Medical-Assistance-in-Dying-Legislation-MAiD.pdf>
15. Council of Canadian Academies. News Release: CCA to Undertake Studies Related to Medical Assistance in Dying. 2016 Nov 14. Available from: <https://cca-reports.ca/council-of-canadian-academies-to-undertake-studies-related-to-medical-assistance-in-dying/>
16. Canadian Conference of Catholic Bishops. Brief submitted to the Special Joint Committee on Physician Assisted Dying. 42nd Parliament, 1st Session. 2016 Feb 24. Available from: https://www.ourcommons.ca/Content/Committee/421/PDAM/Brief/BR8112212/br-external/2016-01-20_PDAM_all%20letters_Cdn_Conf_Catholic_Bishops_Evangelical_Fellowship_of_Cda_e-Final-e.pdf
17. The Canadian Council of Imams. Brief submitted to the Special Joint Committee on Physician Assisted Dying. 42nd Parliament, 1st Session. 2016 Feb 24. Available from: https://www.ourcommons.ca/Content/Committee/421/PDAM/Brief/BR8100883/br-external/councilofimams_PDAM_EN-e.pdf
18. United Church of Canada. Brief submitted to the Special Joint Committee on Physician Assisted Dying. 42nd Parliament, 1st Session. 2016 Feb 24. Available from: https://www.ourcommons.ca/Content/Committee/421/PDAM/Brief/BR8119967/br-external/2016-02-19_brief_United_Church_of_Canada_e-e.pdf
19. Canadian Medical Association. Brief submitted to the Special Joint Committee on Physician Assisted Dying. 42nd Parliament, 1st Session. 2016 Feb 24. Available from: https://www.ourcommons.ca/Content/Committee/421/PDAM/Brief/BR8116310/br-external/2016-02-04_PDAM_follow-up_Cdn_Medical_Association_e-e.pdf

20. The Christian Medical and Dental Society of Canada v. The College of Physicians and Surgeons of Ontario. 2019 ONCA 393. Available from:
<https://www.ontariocourts.ca/decisions/2019/2019ONCA0393.pdf>
21. Council of Canadian Academies. The state of knowledge on medical assistance in dying where a mental disorder is the sole underlying medical condition. Ottawa: The Expert Panel Working Group on MAID Where a Mental Disorder Is the Sole Underlying Medical Condition; 2018. Available from: <https://cca-reports.ca/wp-content/uploads/2018/12/The-State-of-Knowledge-on-Medical-Assistance-in-Dying-Where-a-Mental-Disorder-is-the-Sole-Underlying-Medical-Condition.pdf>
22. Ogilvie K, Oliphant R et al. Medical assistance in dying: a patient centred approach. Report of the Special Joint Committee on Physician-Assisted Dying. 42nd Parliament, 1st Session. 2016 Feb. Available from: <http://eol.law.dal.ca/wp-content/uploads/2016/05/Special-Joint-Committee-on-PAD-FInal-Report.pdf>
23. Chochinov H, Frazee C, Pelletier B. Consultations on physician-assisted dying: summary of results and key findings. External Panel on Options for a Legislative Response to Carter v. Canada; 2015. Available from: <https://www.justice.gc.ca/eng/rp-pr/other-autre/pad-amm/pad.pdf>
24. Health Care Consent Act, 1996, SO 1996, c 2, Sch A. Available from:
<https://canlii.ca/t/5354b>
25. Chochinov H, Tataryn D, Clinch J, Dudgeon D. Will to live in the terminally ill. Lancet. 1999;354:9181. Available from: [https://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(99\)80011-7/fulltext](https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(99)80011-7/fulltext)
26. Canada, Parliament, Special Joint Committee on Physician-Assisted Dying, Minutes of Proceedings and Evidence, 42nd Parl, 1rd Sess, No 008. 2016 Feb 1. Available from:
<https://parl.ca/DocumentViewer/en/42-1/PDAM/meeting-8/evidence>
27. Council of Canadian Academies. The state of knowledge on advance requests for medical assistance in dying. Ottawa: The Expert Panel Working Group on Advance Requests for MAID; 2018. Available from: <https://cca-reports.ca/wp-content/uploads/2019/02/The-State-of-Knowledge-on-Advance-Requests-for-Medical-Assistance-in-Dying.pdf>

28. Health Law Institute, Dalhousie University. Challenges to C-14: end of life law and policy in Canada. Available from: http://eoldev.law.dal.ca/?page_id=2219
29. Lamb and British Columbia Civil Liberties Association v. Canada (Attorney General). Response to Civil Claim. No. S165851, Vancouver Registry, 2016. Available from: http://eoldev.law.dal.ca/wp-content/uploads/2016/10/2016_07_27_Response_to_Civil_Claim.pdf
30. Truchon c. Procureur général du Canada, 2019 QCCS 3792. Found at: <https://canlii.ca/t/j4f8t>
31. Bill C-7 *An Act to amend the Criminal Code (medical assistance in dying)*. Second Session, Forty-third Parliament, 69-70 Elizabeth II, 2020-2021. Available from: <https://parl.ca/DocumentViewer/en/43-2/bill/C-7/royal-assent>
32. AC v. Manitoba (Director of Child and Family Services), 2009 SCC 30 (CanLII), [2009] 2 SCR 181. Available from: <https://canlii.ca/t/24432>
33. Council of Canadian Academies. The state of knowledge on medical assistance in dying medical assistance in dying for mature minors. Ottawa: The Expert Panel Working Group MAID for Mature Minors; 2018. Available from: <https://cca-reports.ca/wp-content/uploads/2018/12/The-State-of-Knowledge-on-Medical-Assistance-in-Dying-for-Mature-Minors.pdf>
34. United Nations Humans Rights Office of the High Commissioner. Convention on the Rights of the Child; 1989. Available from: <https://www.ohchr.org/en/professionalinterest/pages/crc.aspx>
35. Jackman M and McRae A. 1.5.2 Medical decision-making and mature minors. The Royal College of Physicians and Surgeons of Canada; 2013 [cited 2021 July 1]. Available from: <https://www.royalcollege.ca/rcsite/bioethics/cases/section-1/medical-decision-making-mature-minors-e>
36. Consent to Treatment and Health Care Directives Act Regulations, PEI Reg EC356/00, <https://canlii.ca/t/knlh>
37. Archard D. Children, adults, autonomy, and well-being. In: Bagattini A, Macleod C, editors. The nature of children's wellbeing: theory and practice. Springer, Dordrecht; 2015. Chapter 1.

38. Bou-Habib P, Olsaretti S. Autonomy and children's well-being. In: Bagattini A, Macleod C, editors. *The nature of children's wellbeing: theory and practice*. Springer, Dordrecht; 2015. Chapter 2.
39. MacLeod C. Agency, authority, and the vulnerability of children. In: Bagattini A, Macleod C, editors. *The nature of children's wellbeing: theory and practice*. Springer, Dordrecht; 2015. Chapter 4.
40. Cherry M. Ignoring the data and endangering children: why the mature minor standard for medical decision making must be abandoned. *J Med Philos*. 2013;38:3. Available from: <https://pubmed.ncbi.nlm.nih.gov/23615058/>
41. Diekema D. Adolescent refusal of lifesaving treatment: are we asking the right questions? *Adolesc Med State Art Rev*. 2011;22:2. Available from: <https://pubmed.ncbi.nlm.nih.gov/22106736/>
42. Steinberg, L. Does recent research on adolescent brain development inform the mature minor doctrine? *J Med Philos*. 2013;38:3. Available from: <https://pubmed.ncbi.nlm.nih.gov/23607975/>
43. Cohen-Almagor R. Should the Euthanasia Act in Belgium include minors? *Perspectives in Biology and Medicine* 2018;61:2. Available from: <https://pubmed.ncbi.nlm.nih.gov/30146521/>
44. Mullin A. Children, paternalism and the development of autonomy. *Ethic Theory Moral Prac*. 2013;17. Available from: <https://link.springer.com/article/10.1007/s10677-013-9453-0>
45. Coughlin K. Medical decision-making in paediatrics: Infancy to adolescence. *Paediatr Child Health* 2018;23:2. Available from: <https://www.cps.ca/en/documents/position/medical-decision-making-in-paediatrics-infancy-to-adolescence>
46. Alderson P. Competent children? Minors' consent to health care treatment and research. *Soc Sci Med*. 2007;65:11. Available from: <https://pubmed.ncbi.nlm.nih.gov/17854964/>
47. Hester M. Ethical issues in paediatrics. In: Hester M, Schonfeld, editors. *Guidance for healthcare ethics committees*. Cambridge: Cambridge University Press; 2012. Chapter 15. Available from: <https://www.researchgate.net/profile/D->

- [Hester/publication/285743959_Ethical_issues_in_pediatrics/links/5ade38eeaca272fdaf88f76d/Ethical-issues-in-pediatrics.pdf](https://pubmed.ncbi.nlm.nih.gov/18096360/)
48. Chan R, Shum K, Touloupoulou T, Chen E. Assessment of executive functions: Review of instruments and identification of critical issues. *Archives of Clinical Neurophysiology* 2008;23. Available from: <https://pubmed.ncbi.nlm.nih.gov/18096360/>
 49. Bovens L. Child Euthanasia: Should we just not talk about it? *Journal of Medical Ethics* 2015;41:8. Available from: <https://www.jstor.org/stable/44014168>
 50. Kaczor C. Against euthanasia for children: A response to Bovens. *Journal of Medical Ethics* 2016;42:1. Available from: <https://www.jstor.org/stable/44014296>
 51. Schweiger G, Graf G. Ethics and the dynamic vulnerability of children. *The Ethics Forum*. 2017;12, 2-3. Available from: <https://www.erudit.org/en/journals/ateliers/1900-v1-n1-ateliers03964/1051284ar.pdf>
 52. Benporath, S. Autonomy and vulnerability: on just relations between adults and children. *Journal of Philosophy and Education*. 2003;37:1. Available from: <https://onlinelibrary.wiley.com/doi/abs/10.1111/1467-9752.3701009>
 53. Friedman Ross L. Against the tide: arguments against respecting a minor's refusal of efficacious life-saving treatment. *Camb Q Healthc Ethics*. 2009;18:3. Available from: <https://pubmed.ncbi.nlm.nih.gov/19460233/>
 54. Anderson J. Autonomy and vulnerability entwined. In: Mackenzie C, Rogers W, Dodds S, editors. *Vulnerability: new essays in feminist philosophy*. Oxford: Oxford University Press; 2014. Chapter 5.
 55. Mullin A. Children, paternalism, and the development of autonomy. *Ethical Theory and Moral Practice*. 2014;17:3. Available from: <https://link.springer.com/article/10.1007/s10677-013-9453-0>
 56. Raus, K. The Extension of Belgium's euthanasia law to include competent minors. *J Bioeth Inq*. 2016;13:2. Available from: <https://pubmed.ncbi.nlm.nih.gov/26842904/>
 57. Government of the Netherlands [Internet]. Euthanasia, assisted suicide and non-resuscitation on request. [cited 2021 July 1]. Available from:

<https://www.government.nl/topics/euthanasia/euthanasia-assisted-suicide-and-non-resuscitation-on-request>

58. BBC [Internet]. Netherlands backs euthanasia for terminally ill children under-12; 2020 Oct 14 [cited 2021 July 1]. Available from: <https://www.bbc.com/news/world-europe-54538288>
59. United Nations Humans Rights Office of the High Commissioner [Internet]. International human rights law; 1996-2021 [cited 2021 July 1]. Available from: <https://www.ohchr.org/en/professionalinterest/pages/internationalallaw.aspx>
60. Canadian Bar Association [Internet]. UN Convention on the Rights of the Child; 2021 [cited 2021 July 1]. Available from: <https://www.cba.org/Publications-Resources/Practice-Tools/Child-Rights-Toolkit/overarchingFramework/UN-Convention-on-the-Rights-of-the-Child>
61. Byrick K, Walker-Renshaw B. A practical guide to mental health and the law in Ontario. Ontario Hospital Association; 2016. Available from: <https://campusmentalhealth.ca/wp-content/uploads/2018/03/Mental-Health-Law.pdf>
62. Government of Canada [Internet]. Canada's health care system; 2016 [cited 2021 July 1]. Available from: <https://www.canada.ca/en/health-canada/services/canada-health-care-system.html>
63. *An Act Respecting End of Life Care* 2014, chapter S-32.0001. Available from: <http://legisquebec.gouv.qc.ca/en/pdf/cs/S-32.0001.pdf>
64. *Medical Consent of Minors Act, SNB 1976, c M-6.1*, <https://canlii.ca/t/52m20>
65. *Substitute Decisions Act, 1992, SO 1992, c 30*, <https://canlii.ca/t/549vh>
66. *Child, Youth and Family Services Act, 2017, SO 2017, c 14, Sch 1*, <https://canlii.ca/t/54x3z>
67. *Malette v. Shulman* (Ont. C.A.), 1990 CanLII 6868 (ON CA), <https://canlii.ca/t/g1757>
68. *Fleming v. Reid*, 1991 CanLII 2728 (ON CA), <https://canlii.ca/t/1p78q>
69. *R. v. Morgentaler*, 1988 CanLII 90 (SCC), [1988] 1 SCR 30, <https://canlii.ca/t/1ftjt>
70. *Ciarlariello v. Schacter*, 1993 CanLII 138 (SCC), [1993] 2 SCR 119, <https://canlii.ca/t/1fs48>
71. Griffith R. What is Gillick competence? *Hum Vaccin Immunother*. 2016;12:1. Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4962726/>

72. J.S.C. v. Wren, 1986 ABCA 249 (CanLII), <https://canlii.ca/t/2dl00>
73. Van Mol v. Ashmore, 1999 BCCA 6 (CanLII), <https://canlii.ca/t/54n2>
74. Sandland R. Children and consent to treatment. *The Journal of Forensic Psychiatry & Psychology*. 1992;3:1. Available from:
<https://www.tandfonline.com/doi/abs/10.1080/09585189208407631?journalCode=rjfp19>
75. Sandland R. Minors and consent to treatment. *The Journal of Forensic Psychiatry & Psychology*. 1993;4:1. Available from:
<https://www.tandfonline.com/doi/abs/10.1080/09585189308407799?journalCode=rjfp19>
76. Gilmore J. Death, dying and decision-making about end of life care. In: Downie J, Caulfield T, Flood C, editors. *Canadian health law and policy*, 4th ed. LexisNexis Canada; 2011. Chapter 9.
77. Murray S, Lemieux T. The time of a life: ethics and care in the case of a young First Nations girl. In: Blum A, Murray S, editors. *The ethics of care: moral knowledge, communication, and the art of caregiving*, 1st ed. Routledge; 2016. Available from:
<https://www.taylorfrancis.com/chapters/edit/10.4324/9781315616162-13/time-life-ethics-care-case-young-first-nations-girl-first-nations-girl-stuart-murray-tad-lemieux>
78. Hamilton Health Sciences Corp. v. D.H., 2014 ONCJ 603 (CanLII). <https://canlii.ca/t/gf8sg>
79. Government of Canada [Internet]. Section 7 – Life, liberty and security of the person. Department of Justice; 2021 [cited 2021 July 1]. Available from:
<https://www.justice.gc.ca/eng/csj-sjc/rfc-dlc/ccrf-ccd/check/art7.html>
80. Canada (Attorney General) v. Bedford, 2013 SCC 72 (CanLII), [2013] 3 SCR 1101.
<https://canlii.ca/t/g2f56>
81. MacIntosh C. Carter, medical aid in dying, and mature minors. *McGill J.L. & Health*. 2016;10:1. Available from:
https://mjlmcgill.files.wordpress.com/2017/07/mjlh_10_1_macintosh1.pdf
82. Canadian Foundation for Children, Youth and the Law v. Canada (Attorney General), 2004 SCC 4 (CanLII), [2004] 1 SCR 76. <https://canlii.ca/t/1g990>

83. Canadian Charter of Rights and Freedoms, s 15, Part 1 of the Constitution Act, 1982, being Schedule B to the Canada Act 1982 (UK), 1982, c 11. Available from: <https://laws-lois.justice.gc.ca/eng/const/page-12.html#h-40>
84. R. v. Kapp, 2008 SCC 41 (CanLII), [2008] 2 SCR 483. <https://canlii.ca/t/1z476>
85. Council of Europe. Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine. 1997. Available from: <https://rm.coe.int/168007cf98>
86. Gosselin v. Québec (Attorney General), 2002 SCC 84 (CanLII), [2002] 4 SCR 429. <https://canlii.ca/t/1g2w1>
87. Manitoba Law Reform Commission. Minors consent to healthcare. Report no. 91. 1995. Available from: http://www.manitobalawreform.ca/pubs/pdf/archives/91-full_report.pdf
88. M and The Queen, Re, 1985 CanLII 3516 (MB QB). <https://canlii.ca/t/gd8sl>
89. R. v. Rebic, 1985 CanLII 643 (BC SC), <https://canlii.ca/t/22kjp>
90. R. v. Music Explosion Ltd., 1989 CanLII 7484 (MB QB), <https://canlii.ca/t/gdbhd>
91. R. v. Music Explosion Ltd., 1990 CanLII 11042 (MB CA). <https://canlii.ca/t/gbj84>
92. R. v. Music Explosion Ltd., 1996 CanLII 18019 (MB QB), <https://canlii.ca/t/g9swb>
93. l'Heureux Dube C. The dissenting opinion: the voice of the future? Osgood Hall Law Journal. 2000;38:3. Available from: <https://digitalcommons.osgoode.yorku.ca/ohlj/vol38/iss3/4/>
94. Macfarlane E. Positive rights and section 15 of the Charter: addressing a dilemma. National Journal of Constitutional Law. 2018;38:1. Available from: <https://www.proquest.com/docview/2016345807>
95. Ferguson L. The end of an age: beyond age restrictions for minors' medical treatment Decisions. 2004. Available from: <https://dalspace.library.dal.ca/bitstream/handle/10222/10255/Ferguson%20Research%20Minors%20and%20Medical%20Treatment%20EN.pdf?sequence=1&isAllowed=y>
96. Singer P. Voluntary euthanasia: a utilitarian perspective. Bioethics. 2003;17:5. Available from: <https://onlinelibrary.wiley.com/doi/abs/10.1111/1467-8519.00366>

97. Janvier A, Farlow B, Verhagen E, Barrington K. End-of-life decisions for fragile neonates: navigating between opinion and evidence-based medicine. *Arch Dis Child Fetal Neonatal*. 2017;102:2. Available from: <https://pubmed.ncbi.nlm.nih.gov/27974340/>
98. E.J.G. (Re), 2007 CanLII 44704 (ON CCB). <https://canlii.ca/t/1tcqj>
99. Consent and Capacity Board. About us. 2012-2021 [cited 2021 July 1]. Available from: <http://www.ccboard.on.ca/scripts/english/aboutus/index.asp>
100. Consent and Capacity Board. Information sheets. 2012-2021 [cited 2021 July 1]. Available from: <http://www.ccboard.on.ca/scripts/english/publications/infosheets.asp>
101. Law Commission of Ontario. Legal capacity, decision-making and guardianship. Toronto; 2017 Mar. Available from: <http://www.lco-cdo.org/wp-content/uploads/2017/03/CG-Final-Report-EN-online.pdf>
102. Archard D, Skivenes M. Balancing a child's best interests and a child's views. *Int'l J Child Rts*. 2009;17:1. Available from: http://hr.law.vnu.edu.vn/sites/default/files/resources/crc-best_intersts.pdf
103. Ross L, Swota A. The best interest standard: same name but different roles in pediatric bioethics and child rights frameworks. *Perspect Biol Med*. 2017;60:2. Available from: <https://pubmed.ncbi.nlm.nih.gov/29176082/>
104. Gillam L, Sullivan J. Ethics at the end of life: who should make decisions about treatment limitation for young children with life-threatening or life-limiting conditions? *J Paediatr Child Health*. 2011;47:9. Available from: <https://pubmed.ncbi.nlm.nih.gov/21951439/>
105. Lee K, Havens P, Sato T, Hoffman G, Leuthner S. Assent for treatment: clinician knowledge, attitudes, and practice. *Pediatrics*. 2006;118:2. Available from: <https://pubmed.ncbi.nlm.nih.gov/16882829/>
106. Spence K. The best interest principle as a standard for decision-making in the care of neonates. *Journal of Advanced Nursing*. 2000;31:6. Available from: <https://pubmed.ncbi.nlm.nih.gov/10849138/>

107. Verhagen E, Sauer P. The Groningen Protocol — euthanasia in severely ill newborns. *N Engl J Med*. 2005;352. Available from: <https://www.nejm.org/doi/full/10.1056/nejmp058026>
108. American College of Paediatricians [Internet]. Neonatal euthanasia: the Groningen Protocol; 2014 [cited 2021 July 1]. Available from: <https://www.acped.org/position-statements/neonatal-euthanasia-the-groningen-protocol>
109. de Vos M, van der Heide A, Maurice-Stam H, Brouwer O, Plotz F, Schouten-van Meeteren A, et al. The process of end-of-life decision-making in pediatrics: a national survey in the Netherlands. *Pediatrics*. 2011;127:4. Available from: <https://pediatrics.aappublications.org/content/127/4/e1004>
110. Sibbald R, Chidwick P. Best interests at the end of life: a review of decisions made by the Consent and Capacity Board of Ontario. *Journal of Critical Care*. 2010;25:1. Available from: <https://www.sciencedirect.com/science/article/abs/pii/S0883944109002226>
111. Choong K, Cupido C, Nelson E, Arnold D, Burns K, Cook D, et al. A framework for resolving disagreement during end of life care in the critical care unit. *Clin Invest Med*. 2010, 33:4. Available from: <https://pubmed.ncbi.nlm.nih.gov/20691142/>
112. Dombrecht L, Piette V, Deliens L, Cools F, Chambaere K, Goossens L, et al. Barriers to and facilitators of end-of-life decision making by neonatologists and neonatal nurses in neonates: a qualitative study. *Journal of Pain and Symptom Management*. 2020;53:3. Available from: <https://www.sciencedirect.com/science/article/abs/pii/S0885392419305962?via%3Dihub>
113. Schaller C, Kessler M. On the difficulty of neurosurgical end of life decisions. *J Med Ethics*. 2006;32:2. Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2563335/>
114. Ancel P, Goffinet F, EPITAGE-2 Writing Group. Study protocol: EPIPAGE 2: a preterm birth cohort in France in 2011. *BMC Pediatrics*. 2014;14:97. Available from: <https://bmcpediatr.biomedcentral.com/track/pdf/10.1186/1471-2431-14-97.pdf>
115. Michelson K, Koogler T, Sullivan C, del Pilar Ortega M, Hall E, Frader J. Parental views on withdrawing life-sustaining therapies in critically ill children. *Arch Pediatr Adolesc*

- Med. 2009;163:11. Available from:
https://jamanetwork.com/journals/jamapediatrics/articlepdf/382337/poa90043_986_992.pdf
116. L. (Re), 2008 CanLII 46902 (ON CCB). <https://canlii.ca/t/20rtp>
117. C. (Re), 2009 CanLII 41524 (ON CCB). <https://canlii.ca/t/2526n>
118. Mantluak A. “Best interest” and pediatric end stage kidney disease: the case of baby M. *Journal of Pediatric Nursing*. 2019;46. Available from:
<https://www.sciencedirect.com/science/article/abs/pii/S0882596318305025>
119. JM (Re), 2011 CanLII 7955 (ON CCB). <https://canlii.ca/t/2ftdh>
120. CN (Re), 2014 CanLII 53714 (ON CCB). <https://canlii.ca/t/g911b>
121. SS (Re), 2015 CanLII 44140 (ON CCB), <https://canlii.ca/t/gk9pz>
122. Sibbald R [Internet]. Consent and Capacity Board cases addressing end of life decisions. Western University Health Ethics and Policy Lab; [cited 2021 July 1]. Available from: <https://www.uwo.ca/fhs/helplab/affiliates/index.html>
123. Scardoni v. Hawryluck, 2004 CanLII 34326 (ON SC). <https://canlii.ca/t/1gcdr>
124. Cuman G, Gastmans C. Minors and euthanasia: a systematic review of argument-based ethics literature. *Eur J Pediatr*. 2017;176:7. Available from:
<https://pubmed.ncbi.nlm.nih.gov/28573404/>
125. Guichon J, Mohamed F, Clarke K, Mitchell I. Autonomy and beneficence in assisted dying in Canada: the eligibility of mature minors. *Alberta Law Review*. 2017;54:3. Available from: <https://www.albertalawreview.com/index.php/ALR/article/view/774/767>
126. Rietjens J, van der Heide A, Robijn L. Euthanasia for minors in Belgium. *JAMA*. 2014;312:12. Available from: <https://jamanetwork.com/journals/jama/article-abstract/1906604>
127. Sumner L. *Assisted death: a study of ethics and law*. Oxford: Oxford University Press; 2011.
128. Chambaere K, Roelands M, Deliens L. Euthanasia for minors in Belgium. *JAMA*. 2014;312:12. Available from: <https://jamanetwork.com/journals/jama/article-abstract/1906603>

129. Samanta J. Children and euthanasia: Belgium's controversial new law. *Diversity and Equality in Health and Care*. 2015;21:1. Available from: <https://diversityhealthcare.imedpub.com/children-and-euthanasia-belgiums-controversial-new-law.php?aid=3729>
130. Siegel A, Sisti D, Caplan A. Pediatric euthanasia in Belgium disturbing developments. *JAMA*. 2014;311:19. Available from: <https://jamanetwork.com/journals/jama/article-abstract/1863566>
131. Siegel A, Sisti D, Caplan A. Euthanasia for minors in Belgium. *JAMA*. 2014;312:12.
132. Dong A, Wen A. Ethics of Paediatric Medical Assistance in Dying. *Meducator*. 2018;1:34. Available from: https://issuu.com/themeducator/docs/the-meducator_issue-34-11272018-web
133. Sanchini V, Nardini C, Boniolo G. The withholding/withdrawing distinction in the end-of-life debate. *Multidisciplinary Respiratory Medicine*. 2014;9:13. Available from: <https://mrmjournal.org/mrm/article/view/645/634>
134. Keown J. A right to voluntary euthanasia? Confusion in Canada in Carter. *Notre Dame Journal of Law, Ethics & Public Policy*. 2014;28:1. Available from: <https://scholarship.law.nd.edu/cgi/viewcontent.cgi?article=1718&context=ndjlepp>
135. Liao L, Chan D. Physician-hastened death in young children: getting to underlying assumptions. *Paediatr Child Health*. 2016;21:4. Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4934156/>
136. Carter B, Pitts B, Linebarger J, Garrett J, Lantos J. Getting comfortable with death. Our answer to Belgium: palliative care for children is preferable to euthanasia. *Missouri Medicine*. 2014;111:5. Available from: <https://pubmed.ncbi.nlm.nih.gov/25438353/>

Appendix

Appendix A: Summaries of Seven CCB Form G Cases on Paediatric End-of-Life Decisions

Re EJG (2007)

EJG was an eight-month-old infant who had suffered oxygen deprivation in the hours before his birth, which resulted in a brain injury leaving him in a vegetative state and dependent upon a ventilator to assist his breathing. EJG's treatment team proposed that EJG be weaned from the ventilator as an end-of-life measure. If EJG could not breathe and survive independently without a ventilator, the treatment team proposed that he be allowed to die. The team justified the decision based on the futility of further treatment, which would confer no medical benefit to EJG and risked further medical complications and hospital-borne infections. The team asserted that EJG could not feel pain or discomfort, but was experiencing suffering in response to invasive procedures as well as existential suffering. Mrs. G and Mr. G, EJG's parents and substitute decision-makers, would not consent to the care plan, as they did not agree that further treatment for EJG would be futile. This was partially based on distrust of medical opinions of EJG's prognosis, but also based on the belief that God would heal their son. Meanwhile, Mrs. G believed that EJG could not be suffering if he was not experiencing pain or discomfort. The parents' refusal was challenged with an application to the CCB to determine whether refusing the care plan was in accordance with the HCCA.

EJG was not capable, and had no values, beliefs, or previously expressed wishes to inform the treatment decisions made on his behalf. The CCB decision was therefore made completely on the basis of best interests. In the decision, risk was calibrated in terms of when, how, and what happens to a person until he or she dies as opposed to whether a person dies. Further, by basing their treatment decision only in their faith in divine intervention, EJG's parents were found not to be making a decision in their child's best interests. The CCB gives two main reasons: 1) EJG's day-to-day condition or well-being and the likelihood he would endure further medical complications resulting from his brain injury were not considered. Further, EJG's parents did not weight the benefits of treatment against the risk 2) EJG's parents made treatment decisions based on their beliefs rather than his. EJG has not lived long enough to formulate capable values and beliefs to make a treatment decision based on belief in divine intervention.

L (2008)

L was two years old when she suffered burns over 40% of her body, with the burns ranging from superficial to deep. Upon arrival to London Health Sciences, L suffered from shock which progressed to respiratory failure requiring aggressive volume resuscitation, intubation and mechanical ventilation. She also required significant pain control, comfort care and wound care. The team recommended debridement and skin grafting, a plan of care that is time sensitive (seven to ten days). Without the recommended plan of care, the team expected that L would suffer increased pain, experience lifelong disability, and risk fatal infection.

L's parents would not consent to the plan of care proposed by the team. According to the team, the parents had an alternate plan of taking their child to a hospital in Michigan where B&W cream with burdock leaves could be provided. A physician at the Michigan said the hospital would not accept intubated and ventilated children, and that they had serious concerns about L's transportation to Michigan. They also quoted a 50% mortality rate for burns covering 50% of the body. In spite of learning this, L's mother affirmed her faith that that B&W cream with burdock leaves would be best for L and would manage her pain.

The CCB determined that L's parents were not acting in the best interests of their child and that L's best interests were served by accepting and adhering to the treatment plan posed by the team. The CCB agreed with the evidence provided by the team that debridement and skin grafting was current best medical practice, that the treatment would improve her condition and prevent/reduce deterioration, and that the benefit L would receive from the treatment outweighed risk of harm to her. Moreover, while B&W cream with the burdock leaves was a less intrusive alternative, it would not be as beneficial as the proposed care plan, and hence was not a viable clear alternative to skin grafting and debridement.

Re C (2009)

C was a two-and-a-half-year-old girl, who was born "flat" to an Rh negative mother by an emergency Caesarean section at 37 weeks gestation. She sustained hypoxic ischemic encephalopathy (injury due to lack of oxygen) at birth, which led to development delay as well as a number of medical issues. C was hospitalized on multiple occasions for respiratory distress due to aspiration pneumonia between 2008 and 2009. In 2009 a procedure was performed to prevent such aspirations, but the intervention led to an almost complete right-lung collapse, and C developed increased respiratory distress. A non-invasive positive pressure ventilation was used in an attempt to open up her right lung. It produced only a slight improvement and C was therefore intubated with an endotracheal tube. The length of

time C was intubated as well as the number of intubations resulted in significant narrowing of her airway due to extensive swelling and scarring. As a result, C was intubated and on a mode of ventilation called “pressure support” on minimal settings in the Paediatric Critical Care Unit.

The team proposed a tracheostomy to overcome the airway obstruction. The tracheostomy would secure C’s airway, enabling her to breathe more easily and allow for periods off the ventilator. Removing the endotracheal tube would improve mobility, speech, and feeding. Meanwhile C’s parents expressed that while they would do “whatever it takes” and “believe ... in the impossible,” they did not want to use technology to interfere with God’s plan. They also expressed concerns with C’s quality of life, as she had been hospitalized for the previous two months, and was not being raised by her family. C’s parents also appealed to medical advice to choose a “comfort method” of treatment for C, which was recommended before a tracheostomy was offered, and in response to risks that would be avoided by a tracheostomy. Learning new information regarding the risks and benefits of the tracheostomy did not change their decision.

The CCB determined that C’s parents did not comply with the principles for substitute decision-making, particularly with respect to weighing the risks and benefits in comparing accepting and refusing treatment. The proposed tracheostomy would overcome the upper airway obstruction, and would facilitate other therapies that might allow C to come off 24-hour ventilation. Meanwhile, ventilation through the endotracheal tube was a short-term solution, where long-term use would produce further complications and lead to death. The CCB did not formally state that C’s parents made decisions based on their own values rather than in terms of their child’s best interests, but in their evidence the CCB noted that C’s father stated that he drew a line at depending on a machine to breathe, claiming that he would not want to live like that.

Re W (2009)

Baby M was a four-year-old child with renal cystic dysplasia who required a kidney transplant. While M was in gestation, a routine prenatal ultrasound discovered an abnormal finding of bilateral cystic kidneys, and M’s parents sought consultation by paediatric nephrology. M’s parents were informed that there was a likelihood their daughter would be born with damage to her kidneys, though the extent and implications of the damage would be unknown until her birth. M and her parents were of Mennonite descent, residing in a rural Mennonite community. M’s parents had the initial position that they did not want to consider standard treatments of dialysis and transplantation for their daughter.

M was born at 38 weeks gestation. Postnatal imaging confirmed the initial prenatal finding of renal cystic dysplasia, though there was no requirement for immediate intervention for her kidney abnormalities. Until age 4, M's renal function remained relatively stable, and M's parents were diligent in ensuring her adherence to medication and diet, monitoring her blood pressure and weight, and regular following up with her family physician for blood work to check M's kidney function. At age 4, M's blood work indicated decreased kidney function, necessitating initiating renal replacement therapy, where refusing treatment posed a risk to M's overall growth and development. M's parents were reluctant to consent to initiate therapy, preferring to care for M at home. M's condition progressed to reach a critical point where she required a kidney transplant, or at least dialysis as an interim option. Without treatment, M risked neurodevelopmental complications, cardiac risks, anemia, and subsequently an overall poorer quality of life.

M's parents refused dialysis and transplantation. They were well informed, consulted with members of their community, and were fully aware that this decision would likely lead to M's eventual death within the next weeks to months. Yet M's parents based their decision on their trust and belief in God. They claimed that M's fate should be placed in God's hands, and that their only wish for M was for her to "die happily and peacefully in God's grace." Further, the family argued that dying as an innocent child served M's welfare based on their religious belief that life was better in heaven than on earth. The CCB ruled in favour of the health care team, finding that accepting and adhering to the proposed treatment plan was in M's best interests. The board expressed empathy for M's parents in their beliefs, and the care and devotion they showed to their daughter, but the board maintained that the parents could not ascribe their religious beliefs to their child, asserting that M did not have any values and beliefs. M's best interests were therefore determined based on the balance of risk and benefit of the treatment and its alternatives. The board decided that allowing a child to remain at home with a certain outcome of death when there is a 97–98% chance that she would survive a kidney transplant from a family donor was not acting in the best interests of the child, and that M's best interests would therefore be best served by accepting treatment.

RE JM (2011)

JM was a one-year-old child who suffered a severe and progressive neurodegenerative disease. JM had a deceased sister, ZM, who was born with the same disease. There was unanimous agreement that JM would not recover and that no treatment options existed for his condition. Further, there were concerns about JM's quality of life as he would not interact meaningfully with his environment,

would require ongoing gastrostomy tube feeding and support for cough and pulmonary secretion clearance, and would always be bedbound. As a result, the team proposed a removal of the endotracheal tube (breathing tube) without replacement, a “do not resuscitate” order (DNR) and palliative care. JM’s parents and substitute decision-makers did not consent to the proposed treatment. JM’s parents believed that JM was breathing and responsive, and that his sister’s condition was more severe, and wanted JM home for whatever time he had. JM’s mother expressed distrust of the team. JM’s father maintained a belief in God, and that JM would pass “when God says he should.”

The CCB found that “JM should be allowed to die with dignity and that the treatment for JM, in his best interests, would be removal of the endotracheal tube without replacement, a DNR order and palliative care.” Like EJG, JM was not capable and had no prior expressed wishes, values, or beliefs, and it was found that JM’s parents were ascribing their own values to the child. The CCB confirmed the team’s findings that JM had absolutely no hope or chance of ever recovering. Moreover, the CCB found that JM’s parents were not acting in his best interests by demanding life by any artificial means, as they did not view his situation objectively, nor were they able to put themselves into JM’s position. Part of the judgment appealed to the harms and indignities that further treatment would subject JM to: “After three months in hospital hooked up to tubes and machines, after suffering from the invasion of personal privacy, after suffering human indignities, and with the exacerbated difficulties that would arise because of the tracheostomy, it was time for the parents to say ‘enough.’”

Re CN (2014)

On February 2, 2014, CN was born after a challenging delivery requiring the failed use of forceps for one hour, and eventual Caesarean section delivery. CN was born with a skull step deformity, a frontal skull fracture, and bruising, and was a critically ill and comatose infant with an extremely poor prognosis, requiring transfer to the hospital neonatal intensive care unit (NICU). At three and a half months, CN had suffered a severe and irreversible brain injury, with no developmental capacity. The seven neonatologists caring for CN were unanimous in their view that a plan of care of palliative and comfort measures was in CN’s best interests. Despite numerous attempts to engage with CN’s parents, there were many communication challenges, and the team asked for a CCB decision ordering CN’s parents’ consent to withdraw treatment within 48 hours.

CN’s parents were originally from Uganda, and described themselves as Bible Christians, believing in doing what the Bible says to do. While English was neither parent’s first language, both could read and write English. Both parents said that they would not be able to understand high-level medical

information. CN's parents wanted all treatments maintained, but testified that they had requested copies of hospital records, and a second opinion of their son's condition and the treatment proposed, from an independent expert source. The team denied the request for a second opinion because there was consensus between all seven neonatologists regarding CN's condition and the proposed treatment plan.

The CCB dismissed the application, finding that the team did not adequately inform CN's parents in order for them to provide informed consent to withdrawal of treatment. In particular, CN's injuries at birth were not adequately explained to the parents. Further, the Board found that the parents' request for access to hospital records and a second opinion were reasonable requests for information to make an informed decision. The Board concluded that CN's parents must be provided with (1) all medical records, particularly those with respect to the birth of CN and (2) the requested independent expert opinion from an expert health practitioner as to CN's condition and the proposed treatment, prior to the determination that a Form G application was warranted.

Re SS (2015)

SS was a six-year-old boy who was admitted to McMaster Children's Hospital due to inflammation of his gall bladder. He received treatment with antibiotics, but the infection progressed to his blood, and he developed septic shock. SS also developed issues with his lung function – Acute Respiratory Lung Distress Syndrome (ARDS) – and his condition became life-threatening. SS was transferred to the Intensive Care Unit at The Hospital for Sick Children (Sick Kids) for treatment on a heart-lung machine called extracorporeal membrane oxygenation (ECMO). There was no notable improvement in SS's lung function after three weeks on ECMO, and the team believed that continuation on ECMO was futile. The clinical team recommended discontinuance ECMO, but continuation of all other treatments SS was receiving, including mechanical ventilation and high-frequency oscillation. SS's parents were of the opinion that it was in their son's best interest not to remove the machine at that time.

The CCB determined that there was no clear, cogent, and compelling evidence that SS's parents were not applying the best-interests test in keeping SS alive on ECMO. This meant that SS would remain on ECMO according to his parent's decision on his behalf. The rationale was based on the proportional balance of harms and benefits. Although continued treatment on ECMO constituted an invasion of personal privacy entailing pain and discomfort, the CCB found that the level of pain and discomfort had not reached the point where it outweighed the benefit of pleasure to the point that SS's

parents would be required to say, “Enough is enough,” While the harms to SS included suffering undefined pain and discomfort upon touch, being unable to return home, and being unable to enjoy playing with his favourite toy, SS also experienced benefits, which included contact with his parents, enjoying his favourite videos, and enjoying his mother’s singing.

A significant difference between SS’s case and EJJ’s case is that SS was not in a persistent vegetative state. SS was a sensate person who recognized his parents while awake, grimaced and reacted both metabolically and physically when undergoing routine procedures, and demonstrated purposeful movements (including squeezing his parents hands to give directions). Although being in a sensate state did not precluding withdrawal of treatment, the CCB’s judgment seemed to indicate a high threshold of deterioration and harm was required for withdrawal to be in SS’s best interests. The CCB had ruled in favour of withdrawing life support in the case of SR (2011), but determined that SR was in a far greater state of deterioration and that there was no evidence of SR experiencing any pleasure.