



# Improving the Last Stages of Life

DISCUSSION PAPER



LAW COMMISSION OF ONTARIO  
COMMISSION DU DROIT DE L'ONTARIO

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## LIST OF ACRONYMS

<b>ACE</b>	Advocacy Centre for the Elderly
<b>CCAC</b>	Community Care Access Centre
<b>CCB</b>	Consent and Capacity Board
<b>CHA</b>	<i>Canada Health Act</i>
<b>CPSO</b>	College of Physicians and Surgeons on Ontario
<b>DNR</b>	Do-Not-Resuscitate
<b>HCCA</b>	<i>Health Care Consent Act, 1996</i>
<b>HQO</b>	Health Quality Ontario
<b>HPCO</b>	Hospice Palliative Care Ontario
<b>LCO</b>	Law Commission of Ontario
<b>LHIN</b>	Local Health Integration Network
<b>LSUC</b>	Law Society of Upper Canada
<b>LTCHA</b>	<i>Long-Term Care Homes Act, 2007</i>
<b>MAG</b>	Ministry of the Attorney General
<b>MOHLTC</b>	Ministry of Health and Long-Term Care
<b>OHIP</b>	Ontario Health Insurance Plan
<b>OHRC</b>	Ontario Human Rights Commission
<b>OPCN</b>	Ontario Palliative Care Network
<b>POA</b>	Power of attorney
<b>PSW</b>	Personal support worker
<b>QHPCCO</b>	Quality Hospice Palliative Care Coalition of Ontario
<b>RHPA</b>	<i>Regulated Health Professions Act, 1991</i>
<b>SDA</b>	<i>Substitute Decisions Act, 1992</i>
<b>SDM</b>	Substitute decision-maker

### 3. IMPORTANCE OF CARE IN THE LAST STAGES OF LIFE

#### A. Introduction

This project addresses complex systems for planning and delivering health care in Ontario. During the LCO's consultations several stakeholders, especially in the medical field, asked the LCO to explain how law reform is relevant to what they perceive to be medical, administrative or public policy issues.

In this chapter, we explain the law's contributions to governing the health care sector. We begin by exploring nuanced definitions of what the law is. Then, we discuss fundamental legal rights and principles that must be adhered to in delivering health care and the law's interaction with professional standards of care.

The purpose of this chapter is to clarify the law's expansive reach, but also its limits, and the LCO's approach to law reform.

In contrast, the next chapter of this paper provides detailed information on Ontario's existing law, policy and institutional framework specific to care in the last stages of life (including key government agencies and health care benefits).

#### B. Defining "Law"

##### 1. *The LCO's expansive understanding of the law*

The LCO has an expansive definition of the "law", which includes legislation and case law as well as the policies, institutions and everyday practices necessary to implement the law on the ground. Understood in this way, the law can assume various forms and it can be enforced and shaped by many actors.

To begin, the law includes the decisions of governmental and non-state actors whose authority derives from statute, such as regulatory college standards, tribunal guidelines, and government policies and programs. These types of delegated authority do not require the same rigorous procedures as enacting legislation. However, they are a significant part of the legal system and must conform to fundamental legal frameworks, such as administrative and constitutional law.

Take the College of Physician and Surgeons (CPSO), which is one of the colleges regulated under the *Regulated Health Professions Act, 1991* (RHPA).<sup>90</sup> The CPSO's policies must fit within its mandate under that statute, and they must maintain consistency with the *Human Rights Code*,<sup>91</sup> SDA, HCCA, common law standards of care for physicians and so on. Should these laws change, the CPSO's policies would change. In turn, the CPSO itself might influence the advancement of the common law when its standards are considered by the judiciary.<sup>92</sup>

There are also different legal traditions in Canada, including Indigenous legal traditions and religious laws.<sup>93</sup> These legal traditions are grounded in protected rights that individuals and com-

munities enjoy under the Constitution and human rights statutes.<sup>94</sup> Other rights under these two sources of law include rights to life, liberty and security of the person; language rights; and the right to be free of discrimination based on grounds such as race, national or ethnic origin, sex, age and disability.<sup>95</sup>

Laws can infringe these guaranteed rights on their face or in practice, and one of the roles that law reform agencies assume is to identify areas of concern that may not be readily apparent. Although the LCO cannot declare a law invalid, we may nevertheless recommend measures that would ensure consistency with foundational rights and principles.

Moreover, where we find that a law is valid or appropriate but there are barriers to proper implementation, we may make recommendations about practical tools for implementation, such as pilot programs, education and training, and advocacy supports in the community.

Given the LCO's expansive definition of the law, our analysis and recommendations may thus concern a range of instruments and, also, actors from government ministries to regulatory colleges and community organizations.

## **2. *The limits of the law***

Laws relating to care in the last stages of life can only be a partial answer to the complex medical, administrative, ethical and social issues that run throughout this project. Stakeholders informed the LCO about various constraints that exceed the law's reach and, therefore, limit the project scope. Clinical best practices are an obvious example.

Economic pressures in Ontario must also be taken into account as we formulate our recommendations. In our consultations, we heard about the shortage and inequitable distribution of resources available for care in the community, long-term care homes, hospices and elsewhere. Often facilities lack the resources to provide adequate supports to persons who are ill or frail. And caregivers may be stretched to the limits when they use their own finances to help another. As a general rule, the LCO does not make direct recommendations about policies for specific government expenditures. Our suggestions could nonetheless have an indirect impact on resource allocation insofar as changes to legislation, policies, programs and institutions may require funding.

Additionally, while the law can foster change, it cannot transform society by itself. Perspectives on the value of life and death, prejudices against certain groups and opinions on a patient's best interests illustrate the types of issues that the law can address as a matter of rights and principles, such as safety, equity and dignity. However, the law also exists within the larger context of attitudes and structures that naturally enhance or diminish its effectiveness.

## C. Legal Rights and Principles Affecting Health Care

### 1. *Constitutional rights and principles*

The Constitution Act, 1867 and Constitution Act, 1982, including the Canadian Charter of Rights and Freedoms, lay the foundation for government powers and duties respecting health care and corresponding rights for individuals.

Under the Canada Health Act (CHA), the federal government participates in regulating health care through its constitutional spending powers.<sup>96</sup> The federal government transfers funds to provinces that provide health care services through insurance plans, such as the Ontario Health Insurance Plan (OHIP). Service delivery rests largely with the provinces due to their exclusive authority over hospitals (and other health institutions) and “property and civil rights”, which “has been interpreted broadly by the courts to encompass most professional services”, including health care providers.<sup>97</sup>

There is no constitutional right to health in Canada and the Supreme Court has explained that medicare “is, by its very terms a partial health plan”.<sup>98</sup> The CHA grants conditional funding for the provinces to insure “medically necessary” services provided by hospitals and physicians.<sup>99</sup> Medically necessary services are not defined in standardized criteria and they vary across jurisdictions.<sup>100</sup> But the Act does distinguish them from “extended health care services”, which the provinces are not obliged to fund or administer.<sup>101</sup> Extended services relevant to this project include palliative care in private and long-term care homes not administered by physicians, and medications outside hospital.<sup>102</sup>

The provinces can and do supplement the CHA baseline of core services at their discretion.<sup>103</sup> For instance, the Ontario Drug Benefit Program covers the costs of some prescriptions for persons age 65 and older, living in long-term care or receiving home care.<sup>104</sup> Across the country publicly funded non-core services are inconsistent, there may be limits on eligibility and private co-payments may be charged.<sup>105</sup>

While rights to care arising from the CHA and provincial plans are circumscribed, the Supreme Court has nonetheless found that “where the government puts in place a scheme to provide health care, that scheme must comply with the *Charter*”.<sup>106</sup> In several cases, the Court has also identified what types of government activities violate the *Charter*. Below, we briefly summarize notable findings on the grounds of equality and life, liberty and security of the person:

**Equality (*Charter*, s.15):** Publicly funded health care services must be provided in a non-discriminatory manner. In *Eldridge v. British Columbia (Attorney General)*, the Supreme Court held that requiring deaf persons to pay for communication assistance services they needed to access the same basket of health services as the general public violated s.15 of the *Charter*.<sup>107</sup> As a result, the government was ordered to take positive steps to accommodate deaf persons up to the point of “undue hardship” by providing sign language interpretation necessary for effective communication.<sup>108</sup> Section 15 equality protection does not, however, extend to discrimination claims relating to services that governments have chosen not to include in the basket of medicare services.<sup>109</sup>



**Life, liberty and security (*Charter*, s.7):** The *Charter* protects individuals from criminal sanctions against medical practices that deprive them of fundamental rights and s.7 cases have expressly supported rights for persons with terminal illness and chronic disease.<sup>110</sup> In explaining the invalidity of prohibitions against physician-assisted suicide in *Carter*, the Supreme Court held that s.7 engages principles of autonomy, dignity, quality of life and the right to make decisions about one’s bodily integrity and medical care.<sup>111</sup> Particularly relevant to this project, the Court stated that the Constitution “recognizes the value of life, but it also honours the role that autonomy and dignity play at the end of that life”.<sup>112</sup>

The application of s.7 to health care outside the criminal context is ambiguous.<sup>113</sup> In *Chaoulli v. Quebec (Attorney General)*, the Court split on whether restrictions on private insurance for otherwise publicly funded services infringe s.7 when the public system fails to provide timely, quality care.<sup>114</sup> The case was ultimately decided in the claimant’s favour under Quebec’s provincial rights framework.<sup>115</sup> But “even the justices who read section 7 more liberally emphasize[d] that the Charter does not constitutionalize a positive right to health care”.<sup>116</sup>

As mentioned above, specific constitutional rights have been recognized by the courts regarding health, such as non-discrimination in publicly funded care. Furthermore, the Supreme Court’s decision in *Carter* established a right to physician-assisted dying in Canada. This constitutional right has since been interpreted and incorporated into federal and provincial measures for the planning and delivery of medical assistance in dying. We discuss these developments more in-depth in chapter 4.

However, a positive right to palliative care has not yet been adjudicated in Canada. Quebec’s *An Act Respecting End-of-Life Care* establishes a “right to receive end-of-life care” in facilities, residential hospices and homes in that province.<sup>117</sup> The LCO is aware of legal professionals and community advocates who argue for a national right to palliative care under ss.7 and 15 of the Charter and we will keep abreast of related developments in this project.<sup>118</sup>

Constitutional rights to other forms of health care have also already been asserted on Indigenous and religious grounds.<sup>119</sup> The cases addressing those rights involve complex issues about the interaction of the Constitution with provincial decision-making laws, and we have reserved our analysis of them to more suitable parts of the paper. Only a few observations are notable here.

The first is that the federal government’s power to make laws respecting Indigenous peoples under the *Constitution Act, 1867* complicates governance over health care for Indigenous peoples, both in terms of planning and administration, and individuals’ access to palliative care.<sup>120</sup> Second, faith and cultural communities’ legal advocacy on constitutional grounds attests to concerns that the LCO heard regarding the need to integrate differing values about life, death and treatment into medical perspectives and systems.



For more information on care in the last stages of life for Indigenous peoples, see chapter 5.D.3, and for faith and cultural communities, see chapter 6.G.

## 2. Fundamental provincial rights and principles

Ontario's institutional framework for delivering health care is embedded in statutes that are fragmented across sectors, such as the *Home Care and Community Services Act, 1994* and *Long-Term Care Homes Act, 2007*.<sup>121</sup> Unlike Quebec, British Columbia, Alberta and other jurisdictions with strategies to incorporate palliative care across the system, Ontario is currently formulating its provincial strategy.<sup>122</sup> We present how Ontario's existing regime is developing later in this discussion paper, including specific laws, policies and programs (see chapter 4).

Here, the focus is narrower. This section briefly canvasses three areas of provincial law that (similar to constitutional law) integrate fundamental rights and principles across sectors: health quality, human rights and decision-making.

The ***Excellent Care for All Act, 2010*** articulates an overarching vision for publicly funded "high quality health care" in Ontario.<sup>123</sup> The preamble describes a high quality health care system as

one that is accessible, appropriate, effective, efficient, equitable, integrated, patient centred, population health focused, and safe...<sup>124</sup>

Furthermore, the preamble expresses the belief that supports for patients and caregivers and patients' lived-experience are "a critical element of ensuring the future of our health care system".<sup>125</sup> These acknowledgments directly underpin Ontario's performance measurement and improvement laws, and they could be interpreted as principles that guide separate laws relating to care in the last stages of life (e.g., accessibility, integration and equity).

The Ontario ***Human Rights Code*** (Code) applies more directly to a range of actors in the province as legislation with quasi-constitutional status. The *Code* resembles s.15 of the Charter because its purpose is to uphold and mainstream equality rights.<sup>126</sup> Similarly, it prevails over statutes and regulations, and applies to government activity. However, the *Code* has a wider scope - it also applies to private businesses and organizations, including care settings.<sup>127</sup>

The *Code* requires that services, goods and facilities treat every person equally without discrimination based on race, place of origin, creed, sexual orientation, gender identity, age and disability, among other grounds.<sup>128</sup> Compliance may demand accommodations that meet the needs of disadvantaged persons up to the point of undue hardship.<sup>129</sup>

The *Code* is inspired by principles of inherent dignity, the worth of every person and participation in community life.<sup>130</sup> The ***Accessibility for Ontarians with Disabilities Act*** (AODA) and ***Ontario's Action Plan for Seniors*** have comparable goals with respect to these specific communities, which have an interest in the LCO's project. These two frameworks supplement to *Code* with methods for implementing tailored standards, policies or programs.<sup>131</sup>

Decision-making laws are not the final instance of cross-cutting provincial laws in this context, but they are our last example here.<sup>132</sup> Together, the ***Health Care Consent Act, 1996*** and ***Substitute Decisions Act, 1992*** govern informed consent, advance care planning and substitute decision-making. The HCCA empowers individuals to make decisions for themselves when capable.<sup>133</sup> It

also enables them to express wishes, values and beliefs that SDMs must take into account when making decisions on their behalf, should they become incapable.<sup>134</sup> Health care providers must obtain informed consent from a patient or SDM prior to administering every treatment with very few exceptions stipulated in the HCCA.<sup>135</sup>

The HCCA and SDA codify common law rights to bodily integrity and personal autonomy in decision-making, which the courts have described as “co-extensive” with the constitutional right to security.<sup>136</sup>

### **3. Interactions with professional standards of care**

Professional standards of care are intimately tied to the law. Professional standards of care have several sources: the common law, statute and regulatory college guidance, which may include policies, codes of ethics and guidelines.<sup>137</sup>

In the course of this project, the LCO learned that health care providers sometimes refer to the “standard of care” as a *clinical* determination about beneficial treatment options for a patient. As a legal concept, however, standards of care are much more – they determine what can be reasonably expected of a prudent professional in the circumstances.<sup>138</sup> They encompass clinical judgment about treatment options and non-clinical rights and principles under the law. For instance, standards of care include duties of disclosure and obtaining informed consent.<sup>139</sup>

Standards of care may be defined through case law when individuals allege that providers negligently executed their duties. Negligence law helps to define standards of care insofar as it provides information about what would be expected of a prudent professional faced with the facts at hand. In determining the standard of care, the courts may take into account statute as well as regulatory college guidance. Regulatory college guidance may be informative, though not determinative of the standard of care. In turn, regulatory college guidance and general clinical standards of practice must be updated to be consistent with the law.<sup>140</sup>

Aside from health care professionals, lawyers also provide services to persons who are dying, caregivers and family members. Their respective regulatory colleges are mandated under statute to oversee issues relating to licensing, practice standards, competence, complaints and discipline.<sup>141</sup> For lawyers, the *Law Society Act* applies to the Law Society of Upper Canada, while for health professionals the *Regulated Health Professions Act, 1991* applies broadly to a number of self-governing health professions.<sup>142</sup>

Members of the public who have complaints about the care they receive have several avenues of recourse within and outside regulatory colleges. Many health facilities, such as hospitals, have informal dispute resolution processes. The *Law Society Act* and RHPA also require regulatory colleges to administer complaints resolution procedures.<sup>143</sup> Furthermore, appeals of regulatory college complaints determinations may be available through administrative processes (e.g., HPARB),<sup>144</sup> and the courts may lend an added degree of supervision as a last resort.

Throughout this paper, we consider matters relating to professional ethics and practice. We also review mechanisms that could prevent or resolve disputes prior to making a formal claim.

## D. Questions for Discussion

- 3. What legal rights and principles are important for shaping care and establishing professional standards in the last stages of life?*

## 5. ACCESS TO JUSTICE FOR COMMUNITIES WITH UNMET NEEDS

### A. Introduction

Ontario is committed to equality in access to quality care in the last stages of life, regardless of factors such as age, sexual orientation and identity, socioeconomic status, culture, ethnicity and place of residence.

The type of care required to address the needs of any one individual or group differs. Nevertheless, laws, policies and programs should be sufficiently flexible to address diverse experiences in a manner that is consistent with rights and principles established under the Constitution and Human Rights Code, among other legal frameworks.

This chapter reviews the experiences of communities that face particular barriers accessing care in the last stages of life. It begins with an overview of the issue and a reminder about relevant legal frameworks (see also chapter 3.C). Then, it provides select examples of communities with unmet needs in Ontario.

### B. Difficulties Achieving Equality in Access to Care in Ontario

Recent government reviews of palliative care confirm that Ontarians suffer marked disparities in accessing quality care in the last stages of life. For instance, the *Declaration of Partnership* (Ontario's vision for palliative care), the Auditor General report on palliative care, and the Fraser Report identify inequalities based on a variety of factors.

The Auditor General's report highlights that, in many ways, Ontario's difficulties achieving equality arise from the lack of a systemic approach to identifying persons who might be eligible for palliative care and the unequal distribution of services across regional LHINs. By way of example, the Auditor General found, "Because eligibility for and supply of palliative care services varies, patients who qualify for services in one area of the province may not have access to similar services in another area".<sup>349</sup>

The LCO is aware that the OPCN will be addressing systemic barriers relating to Ontario's decentralized institutional framework and the standardization of eligibility criteria, which may go a long way in bridging disparities in access. Furthermore, as recommended by the Auditor General, the Ontario government is developing a province-wide strategy.<sup>350</sup>

However, a range of other complex factors contributes to inequality in access. These factors overlap with issues surrounding basic eligibility and coordination, but they reflect **the diversity in experiences that must also be accounted for within any standardized approach.**

There is a dynamic relationship – sometimes tension – between standardized approaches and ensuring a level of customization that meets the unique needs of individuals, families and communities. For example, palliative care recognizes a set of core principles for treatment and accompaniments as well as the necessity of person- and family-centred approaches in each

specific case (see section 4.C.1). Consistent with “personalization” in palliative care, the LCO also believes that care in the last stages of life must respond to Ontario’s diverse *communities*.<sup>351</sup>

The Fraser Report raises awareness about the place of diversity in achieving equality in access. It relates information that stakeholders told the government and which mirrors what the LCO learned in our own consultations. According to Fraser,

If we were to take only one idea away from our province-wide consultations about palliative care, it would be that not all Ontarians have the same access. The barriers are many and diverse. They range from system fragmentation to geography to challenges providing culturally sensitive care.<sup>352</sup>

Fraser describes various communities affected by disparities in access, and he conveys a message that the LCO also heard repeatedly: Ontario should seek to respond to diverse communities with unmet needs. In his words,

Participants told us, time and again, about the importance of ensuring that all patients have access to culturally appropriate and safe palliative and end-of-life care, including those from urban, rural and remote communities, and including various cultural faith and linguistic groups, vulnerable populations (e.g., people who are homeless, have mental health or addiction issues), people with disabilities and Indigenous communities.

We also heard that the approach to palliative care should be tailored to each unique community.<sup>353</sup>

Not unlike the Fraser Report and Auditor General’s report, the *Declaration of Partnership* acknowledges there are groups that are underrepresented or marginalized in the current system. Furthermore, in that document, partners including the Government of Ontario, LHINs and community organizations, positively committed to “[p]rovide more equitable access across all population groups”.<sup>354</sup>

These and other documents attest to Ontario’s recognition of and commitment to achieving equality in palliative care, and the LCO believes that any future strategy should further such existing commitments. Additionally, from the LCO’s perspective, equality should go beyond access to palliative care to include medical assistance in dying (as defined by law) and, also, certain social and legal benefits that could achieve just outcomes for the many communities affected by death and dying. For instance, ensuring caregivers receive support when providing informal services to persons who are dying would fit within our broad understanding of equality for persons affected by this area of the law and, generally, our definition of access to justice.

The following table lists communities that have been identified as having unmet needs in documents including the Fraser Report, *Declaration of Partnership* and Auditor General’s report. It should be apparent from this table that, collectively, **these communities represent a significant proportion of Ontarians.**

To illustrate the need for customized care, we give examples of difficulties that at least some communities encounter later in the chapter.

FIGURE 5: Ontario’s Communities with Unmet Needs	
• Caregivers, and other family and friends	• First Nations, Inuit and Métis peoples
• Older adults with serious frailties	• Faith and culturally diverse communities
• Persons living in long-term care	• Newcomers to Canada
• Persons living in retirement homes	• Persons living in correctional facilities
• Francophone persons	• Persons living with HIV/AIDS
• Person for whom English is not a principal language	• Persons with mental health issues and addiction
• Persons experiencing homelessness	• Persons living in rural and remote areas
• Persons with disabilities	• LGBTQ persons
• Children and infants	• Persons with low income

To illustrate the need for customized care, we give examples of difficulties that at least some communities encounter later in the chapter.

**C. Legal Frameworks Relevant to Communities with Unmet Needs**

Chapter 3 of this discussion paper reviewed foundational laws applicable to care in the last stages of life, including the *Constitution*, *Canada Health Act*, *Excellent Care for All Act*, and *Human Rights Code*. Each of these laws speaks to issues of equality in access to care in the last stages of life for persons who are dying and their supporters.

We previously explored equality rights under s.15 of the *Charter*, which requires that public funded services be provided without discrimination based on grounds including age, sexual orientation, ethnic origin, religion or disability. Section 15 of the *Charter* may require that governments take steps to accommodate individuals and groups that suffer discrimination up to the point of undue hardship. However, claims to services that are not already within the basket of publicly funded health care may not necessarily be successful, since medicare coverage under the *Canada Health Act* and OHIP is intended to be a partial plan.

### A Note on “Equality” and “Equity”

In the legal field, we use the term “equality” to describe rights to services without discrimination.

This term recognizes that discrimination may be intentional or an *effect of global measures*. Therefore, equality does not always mean the “same” services for everyone, because standardized services may effectively discriminate against those who have unique needs.

Equality recognizes that positive steps to address discrimination may be required to achieve dignity and participation for all.

The concept of “equity” in the health care sector is aligned with the LCO’s understanding of “equality”.<sup>355</sup>

As mentioned previously in chapter 3, the *Ontario Human Rights Code* provides similar equality protections to s.15 of the *Charter*, but while the *Charter* applies to government, the Code also applies to the private sector, and it covers health services and facilities.

Policies and other guidance documents drafted at the Ontario Human Rights Commission (OHRC) elucidate how equality should be interpreted under the Code. The OHRC has disseminated policies on grounds that may be relevant to how care ought to be provided to Ontario’s diverse communities in the last stages of life. Their policies address

- creed and religious observances,
- gender identity and expression,
- sexual orientation,
- mental health disabilities and addiction,
- language,
- racism and racial discrimination,
- age (for older adults), and
- disability.<sup>356</sup>

Some OHRC guidance documents refer directly to accommodations in the health care sector. For example, in the OHRC policy on creed, the Code is interpreted as requiring “inclusive design”, which “means being aware of differences that characterize people from Code protected groups when making design choices to avoid creating barriers”.<sup>357</sup> In that policy, the OHRC provides the example of creating a “multi-faith prayer/reflection room for persons of diverse faiths to observe their creed beliefs and practices” in a health facility.<sup>358</sup>



Thus, the duty to accommodate as a matter of equality relates not only to the removal of overtly discriminatory barriers, such as obstructive infrastructure for persons with physical disabilities. Rather, it is intended to promote the full participation, dignity and citizenship of all Ontarians, and to foster their diversity. The OHRC explains,

The goal of accommodation is to help everyone have equal opportunities, access and benefits... The duty to accommodate stems, in part, from a recognition that the “normal ways of doing things” in organizations and society are often not “neutral” but rather may inadvertently disadvantage, privilege or better meet the needs of some groups relative to others. Instead of giving special privileges or advantages, accommodations help to “level the playing field” by ensuring that all Ontarians are equally included and accommodated.

“The Ontario *Human Rights Code* is meant to foster a society which will allow diversity to flourish...”<sup>359</sup>

Accommodations under the *Charter* and *Code* do, nevertheless, have their limitations. We mentioned the limitation on claims that allege new programs should be funded to improve the condition of specific groups that go beyond discrimination within the medicare basket of services. Another limitation is the requirement that individuals or groups belong to recognized “grounds” for equality. These grounds are listed in the *Charter* and *Code*, and analogous grounds may be recognized by courts.<sup>360</sup> We listed examples above (e.g., race, disability, age).

To the extent that some of Ontario’s communities with unmet needs in the last stages of life may hold rights associated with these grounds, the *Charter* and *Code* could provide a persuasive rationale for improving access to quality care. The LCO’s role as a law reform agency does not involve assessing the relative merits of any particular community’s equality claims. Nonetheless, we do often recommend systemic changes to existing law and policy frameworks that we believe could potentially advance equality.

For those communities that do not hold rights under a recognized ground or who might not be eligible for services because they exceed the law’s definition of non-discrimination, there are other rights and principles that may be instructive. These rights and principles sometimes overlap with a flexible understanding of equality, and they form part of the LCO’s definition of access to justice.

By way of example, s.7 of the *Charter* protects individuals from criminal sanction against medical practices that deprive them of rights to life, liberty and security of the person. Section 7 cases have expressly supported rights for persons with terminal illness and chronic disease. These include rights to make decisions about medications that alleviate the effects of illness and rights to security from interference with one’s physical and psychological integrity.<sup>361</sup> In *Carter*, the Supreme Court affirmed that concerns about autonomy and quality of life can be treated as liberty and security rights.<sup>362</sup>

In sum, legal rights and principles that are relevant to communities with unmet needs in the context of death and dying include the following:

- The right to equality (*Charter*, s. 15)
- The right to life, liberty and security of the person (*Charter*, s. 7)
- The right to freedom of conscience and religion (*Charter*, s.2)
- Indigenous and treaty rights (*Constitution Act*, 1982, s.35)
- Universality in the terms and conditions to access insured health services under provincial plans (*Canada Health Act*, ss.7(a), 10)<sup>363</sup>
- Accessibility of insured health services that is reasonable, free of financial or other barriers, and free of discrimination (*Canada Health Act*, ss.7(e), 12)<sup>364</sup>
- High quality health care that is accessible, appropriate, effective, efficient, equitable, integrated, patient centred, population health focused, and safe (*Excellent Care for All Act*, 2010, Preamble).

Similar to our approach to equality rights, the LCO's project does not evaluate claims to services based on the above rights and principles. However, we do believe Ontarians should have equitable access to care, and that it might be inconsistent with existing rights and principles if only some communities have access to crucial public services nearing the end of life. Therefore, along with the LCO's own *Framework Principles* (see chapter 1.B), established rights and principles inform our approach to law reform, and we take them into account in this project.

In next section, we mention rights and principles when they relate to our examples of communities facing challenges with this area of the law. For the most part, however, we simply describe the experiences that stakeholders told us about, recognizing that certain communities might benefit from tailored laws, policies or programs.

#### **D. Examples of Communities with Unmet Needs**

It should be clear from our review so far that Ontario is home to many distinctive communities that might benefit from a tailored approach to care. The reasons are complex, involving our Constitutional history, demographic trends, persisting discrimination and interrelated factors. At a high level, we consider the following factors as contributing to the importance of addressing particular needs in a nuanced, responsive manner:

- Dying, death and bereavement affect everyone
- Ontario is a province with a rich tradition of diversity
- Faith, cultural and other values, beliefs and practices have a strong bearing on how we define quality care
- Communities interact differently with the health care system, and sometimes their needs are underrepresented in standardized approaches.

Given the extensive variation in affected individuals and communities, we can provide only a few examples of communities with unmet needs.

Some were chosen as examples due to deficits in research and awareness. For example, we are mindful of the OPCN's plans to improve palliative care across Ontario's geographic regions, and we have not presented them here. We have also funded external papers on LGBTQ persons, and older adults with serious frailties and their caregivers. These are found on our website at [www.lco-cdo.org](http://www.lco-cdo.org). Furthermore, we address faith and cultural issues in a separate chapter because they permeate the experiences of nearly all communities (ch. VI.G).

For a list of these and other communities identified as having unmet needs in Ontario, please see the table on page 73. We also invite you to tell us about any other communities that the LCO should be considering during our consultations for the project.

Finally, the LCO acknowledges that **the discussions below provide only partial information** on the challenges that communities face. This chapter is by no means exhaustive; it is intended to provide helpful illustrations that we can build upon as the project proceeds.

## **1. Caregivers, and other family and friends**

During the LCO's background consultations, we heard that caregivers who support persons nearing the end-of-life, and other family and friends, desire improved services during the course of illness and after a person has died.

### **i. Caregiver supports**

Caregivers play an indispensable role in Ontario's health care system. They provide wide ranging assistance across care settings and substantially supplement publicly funded services.<sup>365</sup> Studies show many caregivers perceive their role in a positive light, as a reciprocal process that benefits them and the persons they support.<sup>366</sup> However, there is also reliable evidence demonstrating that negative health, social and financial repercussions of caregiving are common.<sup>367</sup>

The Change Foundation's 2016 report, *A Profile of Family Caregivers in Ontario* documents the many impacts of caregiving. For instance, it shows that juggling caregiving and work can have a destabilizing effect on employment.<sup>368</sup> Many caregivers report feelings of worry, anxiety, fatigue, depression, loneliness and being overwhelmed.<sup>369</sup> Almost 1 in 10 caregivers also report financial hardship resulting from their responsibilities including borrowing money, using savings and selling their assets.<sup>370</sup>

Presently, caregivers living in Ontario may possibly be eligible for four forms of support:

1. Protected leave from work in designated circumstances
2. Financial support from federal Employment Insurance (EI)
3. Respite care delivered through the provincial health system
4. Income tax credits.

Residents may thus have avenues of recourse open to them, including making an application to the Landlord and Tenant Board if they are being unlawfully evicted as well as submitting a complaint to the Retirement Homes Regulatory Authority.<sup>416</sup>

But, in practice, retirement homes do evict residents or pressure them to leave without applying to the Landlord and Tenant Board.<sup>417</sup> We mentioned above that they have also prohibited residents from accessing external services to which they are entitled (in general and prior to any eviction order).

There are several resources available for residents and others seeking public legal education and advice, such as the Advocacy Centre for the Elderly and Community Legal Education Ontario (CLEO). Nonetheless, the LCO would like to know more about how compliance under the RHA and RTA could be improved, residents' rights better enforced and whether any legislative reform would be beneficial.

#### **4. First Nations, Inuit and Métis peoples**

Health care for Indigenous peoples in Canada is in dire need of reform. Indigenous peoples are affected by shorter life expectancy, higher rates of chronic conditions and distressing health crises.<sup>418</sup> Yet, they lack access to culturally appropriate, self-determined and safe services.<sup>419</sup>

The Truth and Reconciliation Commission's (TRC) *Calls to Action* lists a number of areas for collaboration between Indigenous, federal, provincial and territorial governments to improve health care in these circumstances. It calls upon them to

....acknowledge that Aboriginal health in Canada is a direct result of previous Canadian government policies, including residential schools, and to recognize and implement the health-care rights of Aboriginal people as identified in international law, constitutional law, and under the Treaties.<sup>420</sup>

Over the past year, both the federal and provincial governments have pledged to invest new funding into health for Indigenous communities.<sup>421</sup> Ontario launched the First Nations Health Action Plan to ensure "access to more culturally appropriate care and improved outcomes".<sup>422</sup>

The action plan focuses on a number of critical priorities, including primary care, public health and health promotion, senior's care, and life promotion and crisis support.<sup>423</sup> Initiatives that receive increased funding in these areas could, possibly, devote some funds to palliative care.<sup>424</sup> However, the action plan does not explicitly mention palliative care. The government has promised to implement and review the action plan in partnership with Indigenous partners.<sup>425</sup>

There are extensive barriers to quality care nearing the end of life for First Nations, Inuit and Métis persons in Ontario that must be overcome. In Ontario, Indigenous peoples receive a mix of services delivered through complex arrangements involving federal and provincial funding and services, and First Nations governments. The palliative care that any one individual receives is highly dependent on factors such as status under the *Indian Act*, place of residence within or outside a First Nations jurisdiction, and the geographical location and resources of distinctive First Nation communities.

Given the Ontario government's commitments to palliative care and, also, Indigenous health, the LCO believes it is an opportune time to improve palliative care in a way that addresses disadvantages for Indigenous communities, including inequalities among those communities. To that end, below we describe existing challenges that should be considered.

Needless to say, the LCO cannot speak for Indigenous peoples. In the confines of this discussion paper, we can only describe a handful of barriers that have been already been reported.

These are examples of challenges that we would like to learn more about:

- 1. Divisions between federal and provincial governments create a “gap” in health care:** The federal government regulates and funds health care for First Nations peoples living on reserve.<sup>426</sup> At the same time, Ontario must deliver insured services to everyone residing in the province.<sup>427</sup> Ambiguities arising from this division of power have given rise to “gaps” in care for persons living on reserve.<sup>428</sup> Recently, the Canadian Human Rights Tribunal recognized a robust interpretation of “Jordan’s Principle”, which requires the first agency that is contacted to pay for services for children living on-reserve and to determine jurisdictional issues later.<sup>429</sup> Nevertheless, jurisdictional conflicts affect the availability of palliative care, as special type of service, which we review below.
- 2. Palliative care is inadequate for Indigenous peoples in Ontario:** Federal funding on reserve covers “essential health services”, which include home and community care but not dedicated long-term or palliative care.<sup>430</sup> Individuals living on reserve are eligible for provincial home and community care services as well.<sup>431</sup> However, provincially funded services on reserve vary and are often not available, especially in remote communities.<sup>432</sup> Indigenous peoples located or living off-reserve can generally access the same services as others in the province.<sup>433</sup> In these circumstances there may be cultural, language and other social barriers to access (see below). Moreover, if individuals have to leave their homes on-reserve to receive care for the last stages of life, it can have detrimental effects for them, their family and community.<sup>434</sup> The MOHLTC does fund Aboriginal Health Access Centres (AHAC), which provide some palliative care on and off-reserve.<sup>435</sup> But overall, Indigenous peoples’ access to palliative care is wanting.<sup>436</sup>
- 3. There are inequalities among persons living on and off-reserve, and across First Nations communities:** Inequalities in services between persons living on and off-reserve can be gleaned from the two challenges presented above.<sup>437</sup> These distinctions also affect First Nations, Métis and Inuit individuals differently, since only First Nations receive federally funded services on reserve in Ontario. Although a recent Supreme Court case affirms that the federal government holds obligations toward Métis and Inuit peoples under the *Indian Act* and fiduciary duties, these obligations do not extend to the provision of health care.<sup>438</sup> Additionally, the LCO has heard there are great differences in the demographics, resources and capacities of various First Nations communities across Ontario, depending on complicated factors (e.g., proximity to urban areas).<sup>439</sup>

4. **Self-determination is an important part of health care:** Health care is planned and delivered in partnership with Indigenous governments and agencies. Each reserve has a different arrangement for health care administration. For example, some communities deliver health care through funding agreements between the federal government and Band Council, while others do so in partnership with regional Treaty organizations (e.g., Nishnawbe Aski Nation) or First Nations Health Authorities.<sup>440</sup> The provincial AHACs are community-led and they seek to promote self-determination: 60% of their professionals are Indigenous individuals and they also employ traditional healers (for a total of 360 employees in 10 centres).<sup>441</sup> Even so, the LCO heard that tensions arise in existing governance arrangements, and there is a desire for enhanced self-determination in Indigenous health care.
  
5. **Cultural appropriateness is related to “safety” in health care:** Cultural appropriateness is a goal for all care nearing the end-of-life. Cultural awareness and the ability to provide competent care for Indigenous peoples is sometimes referred to as “cultural safety”.<sup>442</sup> Framing this issue as a matter of safety captures the relationship between mainstream services and Indigenous experiences of colonization, discrimination and oppression, which have continuing, traumatic repercussions on multiple generations.<sup>443</sup> There are certainly efforts in Ontario to build cultural safety into care nearing the end-of-life.<sup>444</sup> However, there is no standardized guidance on cultural safety, and Indigenous beliefs, practices and languages have not been well integrated or reinforced.<sup>445</sup> For the LCO, claims to culturally appropriate health care as a Treaty right and, also, legal disputes about rights to traditional healing under the Constitution shed light on the urgency of articulating the scope of cultural safety.<sup>446</sup> We examine cultural issues, including Indigenous cultural issues, comprehensively in chapter 6 of this paper.

As mentioned above, the TRC’s *Calls to Action* makes recommendations to improve Indigenous health care. Recommendations include recognizing Indigenous healing practices, increasing the number of Indigenous professionals working in health care, and providing compulsory education on Indigenous history, rights, Treaties and practices, among others.<sup>447</sup>

During our consultations, the LCO learned there are many promising palliative care initiatives and pilots in Ontario that affirm Indigenous community mobilization and empowerment, such as the *Improving the End-of-Life Care in First Nations Communities* project conducted with four First Nations communities.<sup>448</sup>

In addition to Indigenous persons’ lived experiences, would like to know more about how these community-based programs and sources, such as the TRC report, might feed into ongoing work.

## **5. Persons experiencing homelessness**

Homelessness affects diverse individuals who are living in extremely vulnerable circumstances – from persons affected by family violence staying in shelters and immigrants in temporary accommodations to “unsheltered” persons living on the streets. Although definitions of homelessness do vary in scope, the Canadian Observatory on Homelessness defines the term inclusively to describe

individuals or family without stable, permanent, appropriate housing, or the immediate prospect, means and ability of acquiring it.<sup>449</sup>

There is a true continuum of situations covered by this term since “homelessness does not discriminate on the basis of age, gender, sexuality or race”.<sup>450</sup> There are, however, groups that disproportionately experience homelessness, including some of persons we mentioned above:

- Persons seeking protection from abuse
- New immigrants
- Persons with mental health issues and cognitive disabilities
- Persons with addiction
- Individuals relocating from institutional care (e.g., group homes, child protection, mental health facilities, correctional facilities).

Persons living with a low income have less access to health services and worse health outcomes, and these consequences are particularly evident among homeless persons.<sup>451</sup> Homeless persons may have overlapping conditions and, frequently, struggle with mental health issues. Yet there are fewer resources available to address their intersecting physical, psychological and social conditions, and the community has a higher morbidity rate than the general population.<sup>452</sup> It is estimated that “[a]t the age of 25, men living in shelters, rooming houses and hotels are expected to live, on average, until 42.3 years”.<sup>453</sup>

When it comes to palliative care, however, stakeholders told the LCO that standard services are not conducive to reaching Ontarians experiencing homelessness and providing them with quality care.

There are certainly barriers unique to different individuals and groups within this community; however, there are also shared challenges. For example, most persons experiencing homelessness do not have a health card.<sup>454</sup> The lack of fixed address makes standard documents a challenge and, in turn, impedes the ability to access the health system as a whole.<sup>455</sup> There are also hospices that refuse to care for individuals without a permanent address or primary care provider – two things that homeless individuals might not have.<sup>456</sup> Even basic emergency services and hospital care may be beyond reach.<sup>457</sup>

Persons experiencing homelessness also tend to have priorities that compete with their health needs. Immediate necessities of life, such as food and shelter, often take precedence over health care, which can lead to delays in seeking help or a lack of continuity in care.<sup>458</sup> Individ-

### iii. First Nations, Inuit and Métis cultural safety

Legal responsibility for health care in First Nations, Inuit and Métis communities in Ontario is complex because it is shared between Indigenous, federal and provincial governments. In chapter 5 of this discussion paper, we outlined key barriers to care for Indigenous peoples living in Ontario. In this section, we consider the necessity of integrating Indigenous beliefs and practices into care nearing the end of life as a matter of “cultural safety”.

The term cultural safety was coined in New Zealand with respect to Maori peoples’ health care. However, it has developed into a way of speaking about culturally appropriate health care for Indigenous peoples around the world, including in Canada.<sup>764</sup>

There is no single definition of cultural safety. Generally, it aims to convey the interconnectedness of Indigenous health with the continuing repercussions of colonization, cultural and social assimilation and persisting systemic discrimination, which have led to trauma within communities and a loss of culture.<sup>765</sup> Health care that does not respond to these factors has been considered to generate “risks” to security.<sup>766</sup>

Cultural safety is sometimes placed on a continuum alongside the term “cultural competence”; however, some proponents consider it to be a “paradigm shift” – a more dramatic change in approach.<sup>767</sup> Whereas cultural competence may be characterized as health care provider education about and sensitivity to various cultures (and, therefore, a service provision model), cultural safety is envisioned as an *outcome* from the patient’s viewpoint. Thus, cultural safety involves awareness about power imbalances between health care providers and Indigenous patients, and a fundamental power shift toward the patient’s experience of quality care.<sup>768</sup>

The Assembly of First Nations describes the shift in location of power and control that cultural safety entails as follows:

The person who receives the services defines whether it was culturally safe. This shifts the power from the provider to the person in need of the service. This is an intentional method to also understand the power imbalance that is inherent in health service delivery.<sup>769</sup>

The National Collaborating Centre for Aboriginal Health has accumulated definitions of cultural safety from organizations that endorse this language, including the National Aboriginal Health Organization, Indigenous Physicians Association of Canada and Canadian Indigenous Nurses Association of Canada. Key aspects of their and other descriptions of cultural safety include

- Analyzing colonial relationships, discrimination and power imbalances
- Having service providers reflect on their own culture and its impacts on their providing care
- Understanding the pervasiveness of health problems within Indigenous communities
- Respecting the patient’s definition of what “safe” service means.<sup>770</sup>



In practice, cultural safety calls upon policymakers, service providers and communities to reformulate approaches to health care. It requires the incorporation of Indigenous understandings of death and dying, healing practices, traditional foods, spirituality, and language and cultural translation, and true engagement with community members in service planning and delivery.

Specific barriers to these goals that the LCO has heard about include the lack of long-term and palliative care on reserves and in rural and remote communities; the insufficiency of paid translators; and the need for spaces that accommodate ceremonies and large groups of people, including immediate family, elders and extended community members. Although not all First Nations, Inuit and Métis individuals will want to access traditional healing, integrating traditional medicine into palliative care approaches has also been said to be important for many diverse groups.<sup>771</sup>

In a paper describing the development of an innovative community-based palliative care program in Six Nations of the Grand River Territory, the authors identified several policy challenges for First Nations communities seeking to develop palliative care, including accessing human resources and equipment, jurisdictional issues as barriers to funding, the need for education and training to develop qualified First Nations healthcare professionals from the community, and the lack of dedicated funding allotted for end of life care in First Nation communities.<sup>772</sup>

As a first step, in terms of the LCO's project, we could consider making recommendations that build on the many best practices that community members brought to our attention. In addition to the program at Six Nations of the Grand River Territory referenced above, examples of best practices in Ontario include the Sioux Lookout Meno Ya Win Health Centre, which primarily serves Anishinabe communities in Northern Ontario, and the Lakehead University *Improving End-of-Life Care in First Nations Communities* project, which is a "bottom-up" model for First Nations capacity-building at the local level.<sup>773</sup> Each of these initiatives is based on principles of community mobilization, self-determination and cultural safety.

### **3. Legal framework for faith and cultural rights**

#### **i. Freedom of religion, provincial human rights and Indigenous rights**

Previous chapters in this paper summarize equality rights under s.15 of the *Charter* and the *Human Rights Code* as well as other rights and principles relevant to ensuring equality and substantive justice in health care services. In particular, chapter 5 addressed legal frameworks germane to communities with unmet needs. Faith and cultural communities are among those with unmet needs and the legal frameworks presented earlier in this paper apply to them. (See also, chapter 3.C, "Legal Rights and Principles Affecting Health Care".)

Here, we supplement prior chapters with a brief account of further rights and principles that could apply to faith and cultural communities: freedom of religion under s.2(a) of the *Charter*, the OHRC policy on creed, and Indigenous rights.

On the whole, these laws do not paint a cogent picture of what rights faith and cultural communities are entitled to on the ground when it comes to requesting positive, culturally competent and safe health care services nearing the end of life. This is due, in part, to tensions between laws. Faith and cultural rights are complicated by their connection with capacity and decision-making, and child protection laws. In some respects, these other laws may already incorporate faith and cultural considerations, albeit as factors to be balanced against other rights and principles (especially, security and wellbeing).

The OHRC policy on creed provides the most pragmatic lessons for the LCO's project due to its focus on positive accommodations across both government and private sectors. The OHRC policy and other sources of rights and principles are summarized below:

1. **Freedom of religion (*Charter*, s.2(a)):** Freedom of religion is protected as a fundamental right under the Constitution.<sup>774</sup> It guarantees individuals and groups freedom from government activity that interferes with their sincerely held religious beliefs and related practices.<sup>775</sup> The relationship between freedom of religion and health care services has not been clearly delineated. The Supreme Court has heard just a few claims where the *Charter* was invoked directly or indirectly to assert a patient or SDM's right to refuse consent to treatment on religious grounds. These cases concern both the right to refuse the provision and withdrawal of treatment.<sup>776</sup> Most recently, religious beliefs have been generally characterized as implicit in "best interests" tests that factor in values and beliefs.<sup>777</sup> Where matters of child protection are involved, the Court has repeatedly split on whether prohibiting a parent to refuse lifesaving treatment on a child's behalf violates s.2(a) of the *Charter*.<sup>778</sup> However, even Justices who found there to be a rights violation have concluded it was justifiable as a reasonable limit.<sup>779</sup>
2. **OHRC policy on creed:** The OHRC describes the Code protections for creed as going beyond freedom of religion under the *Charter*, which it says "is primarily concerned with preserving individual *liberty*".<sup>780</sup> The Code promotes equality and non-discrimination in requiring that individuals and groups "may *equally* access, benefit from, and are equally treated".<sup>781</sup> Under the Code, health care providers and facilities have a duty to accommodate sincerely held beliefs and practices to the point of undue hardship.<sup>782</sup>

Accommodations may require "inclusive design" to remove barriers to full access and participation that flow from standardized policies. They must also be individualized. While persons seeking accommodations must help to secure them, the provider is responsible for putting solutions in place with the person's cooperation.<sup>783</sup>

Based on the OHRC policy, health facilities and providers should assess whether staff have necessary cultural competency. The policy states that cultural competency is "key to recognizing and meeting human rights-related needs of different groups and communities" and gives the example of a hospital that could meet its duties by training staff and maintaining a "roster of counsellors and chaplains on hand to support end-of-life care".<sup>784</sup>

3. **Indigenous rights:** Existing aboriginal and treaty rights are recognized and affirmed under s.35 of the *Constitution Act, 1982*. The definition of “aboriginal peoples” under the Constitution includes First Nations, Inuit and Métis peoples. In chapter 5.D, we explained how First Nations, Inuit and Métis health care is regulated in Ontario. Whether culturally safe health care rises to the level of a constitutional right engages another line of inquiry. One Ontario case considered whether child protection laws violate Indigenous rights, when a parent refused consent to treatment on behalf of her daughter to pursue traditional medicine.<sup>785</sup> That case is controversial and the results, which were subsequently amended, do not provide clarity on the balance of rights in such cases.

Aside from s.35, First Nations assert that the government has a fiduciary duty to provide quality health services to Indigenous peoples.<sup>786</sup> A recent Supreme Court case affirmed that the Ontario government is subject to fiduciary duties in dealing with Indigenous interests in some circumstances; although, it does not speak to fiduciary duties to provide culturally safe health care.<sup>787</sup> It also should be recalled that a new landscape of partnership is forming between Indigenous, federal and provincial governments. The federal and provincial governments have made new funding commitments to Indigenous health to be managed in partnership with Indigenous governments.<sup>788</sup>

The OHRC policy on creed devotes a full chapter to Indigenous spirituality. The policy recognizes a flexible and robust definition of Indigenous spirituality and requires accommodation for Indigenous peoples’ beliefs and practices, including ceremonies and customs. It specifically addresses the need to accommodate smudging in hospitals, for health care providers to develop cultural competency skills, and for extended time for bereavement leave. It also recommends service providers create a complete strategy to prevent and address issues affecting Indigenous spirituality.<sup>789</sup>

Finally, the LCO supports non-binding sources of law, such as the TRC’s *Calls to Action*, which establish compelling objectives for culturally safe health care. In 2016, Canada also ratified the *United Nations Declaration on the Rights of Indigenous Peoples* – an international treaty with standards for the attainment of health, involvement in determining health programs, right to traditional medicines and health practices, and the protection of culture.<sup>790</sup>

Again, it is possible that legal frameworks do not provide the practical guidance required to integrate positive, faith and cultural supports into health care services in the last stages of life. The OHRC policy on creed has the most robust formulation of what equality means in these situations, and it recommends that employers, facilities and health care providers implement concrete strategies to prevent and address diverse faith-related needs.

One question for the LCO’s project is whether the OHRC policy goes far enough in relying on “accommodations” to guarantee supports for what could simply be good, quality care. In this

project, the LCO uses the terminology of “accommodations and supports” to acknowledge that although some services may not be protected rights, they may be part of a person, family and community centered approach to quality care that can be integrated into sectoral laws, discussed below.

## **ii. Sectoral laws: hospital, long-term, home and community care**

Because Ontario’s health care system is fragmented across sectors, separate laws may contain various provisions relating to faith and cultural preferences.

For instance, the *Long-Term Care Homes Act, 2007* and *Home Care and Community Services Act, 1994* establish rights to receive services that respond to preferences based on ethnic, spiritual, religious, linguistic, familial and cultural factors.<sup>791</sup> In developing a plan of care or services, providers must ensure that these factors are incorporated or considered.<sup>792</sup> Moreover, in assisting a resident with placement in a long-term care home, coordinators must consider faith and cultural preferences.<sup>793</sup>

There are long-term care homes in Ontario for First Nations peoples on reserve and for cultural and linguistic communities across the province. Such institutions are protected by provisions of the *Human Rights Code* for special interest institutions.<sup>794</sup> However, the LCO has been told there are too few. A 2016 study found that persons who apply for culturally specific long-term care homes wait longer than other applicants. It explains, “those from linguistic and ethnic minority communities may have to wait for years to enter their preferred homes that serve traditional cuisines and activities and provide care and nursing services by staff who speaks their mother tongues”.<sup>795</sup> The LCO also spoke to service providers who told us that coordinating appropriate faith and cultural supports remains a challenge in home and community care. This can be especially difficult in regions that serve high populations of newcomers to Canada.

With regards to retirement homes, the *Retirement Homes Act, 2010* states that residents have the right to have their “lifestyle and choices respected and to freely pursue [their] social, cultural, religious, spiritual and other interests”.<sup>796</sup> However, as retirement homes are residential tenancies, these rights are limited; they must not substantially interfere with the reasonable enjoyment of the home for the licensee and other residents.<sup>797</sup>

The LCO commissioned research study offers insights into the adequacy of faith and cultural accommodations and supports in hospitals. The authors surveyed 19 leading Ontario hospitals through website searches and the distribution of questionnaires (three hospitals answered the questionnaires). Interviews with health care providers, and faith and community leaders also complemented the research.

Their findings demonstrate that there appears to be no uniform approach across the province to achieving faith and culturally sensitive care. Regulatory colleges and professional associations advise their members to provide services that respond to the faith and cultural needs of their patients, such as the RAO guidelines on cultural competence and the CPSO policies on end of life and human rights.<sup>798</sup> Nevertheless, education for health care providers is variable.

Health care providers indicate they do not feel comfortable providing culturally competent and safe care because they receive little formal education to serve patients in this respect. Aside from the lack of education, they spoke about difficulties with requiring health care providers to take on added areas of competence, which could increase their workload - some said there should be a dedicated person with the expertise to address faith and cultural preferences in facilities.<sup>799</sup>

Currently in hospitals, there are few formal policies on faith and cultural issues.<sup>800</sup> Traditionally, chaplains have played a significant role in care settings as experts in faith counselling. Chaplains may belong to one faith or be able to support patients in multiple faiths and spirituality.<sup>801</sup> Many facilities do not, however, have full-time chaplains and most are Christian, creating inequalities across religious traditions.<sup>802</sup> Additionally, there is a common perception in Ontario that chaplaincy programs are not essential services, and they are the first to be cut when resources are low or system restructuring takes place. Often, patients and families are not asked about their preferences at the bedside and are left to coordinate their own faith and cultural supports.<sup>803</sup>

There are certainly centres of excellence in the province; however, as Latif et al. report, “Where excellent programs exist, they seem to be driven by individual communities and motivated professionals”.<sup>804</sup> The piecemeal approach to integrating cultural competence into care settings has led to inconsistencies in services and, overall, inequalities in access.<sup>805</sup>

The authors of the LCO commissioned paper summarize these and other barriers to integrating faith and cultural preferences as follows:

- Lack of cultural competence in health care
- Inconsistent policies supporting culturally sensitive and faith-based care for all denominations
- Insufficient resources provided to faith-based and cultural supports
- Inadequate consultation with faith and cultural groups in health policy development.<sup>806</sup>

#### **4. Strategies to improve culturally competent and safe care in Ontario**

There are a number of practical challenges in strengthening accommodations and supports for members of faith and cultural communities during the last stages of life.

The complex web of laws and policies surrounding accommodations for faith and cultural communities makes it difficult for those working in this environment to identify responsibilities and good practices. Persons of good will may be genuinely confused or ill-informed on these issues. The challenge is heightened where legal obligations are inconsistent, such as where the duty to accommodate a faith related need is in contradiction to a health and safety requirement.

As well, this is a setting where resources are scarce and pressures are significant, a reality that must be taken into account in crafting strategies towards holistic approaches to care.

Individuals in the last stages of life and their families may not be aware of the available supports, or be in a position to advocate for them. If accommodations or supports are denied, pathways to enforcement are unclear.

There are multiple strategies that could be used to improve culturally competent and safe care in Ontario. The LCO proposes that these strategies should be framed as accommodations and broader supports that may be part of a person-, family- and community-centred approach to quality care.

Possible solutions that service providers and community members spoke to LCO about include creating educational tools for cultural competence and safety. There are several existing manuals that summarize the traditional beliefs and practices of diverse communities respecting health care, such as the Canadian Multifaith Federal information manual, mentioned above. However, it is unclear how widely these resources are disseminated and how well they are working on the ground. The LCO would like to know more about the usefulness of these tools and whether they might be improved to ensure they are not overly general. We would particularly like to know whether such tools would be helpful in the end of life context.

The LCO could also review the possibilities for requiring Ontario's regulatory institutions and care settings to create and implement formal policies on faith and cultural integration. We heard that the LHINs, CCACs, long-term care homes and hospitals do not currently serve diverse populations appropriately in terms of language needs, education about eligibility for health care, providing faith and cultural supports onsite and facilitating contact with leaders in the community. Consequently, we wonder if a more coherent approach to systemic change could be realized through a mandatory policy approach.

Although the LCO's understanding of faith and cultural competence and safety goes beyond accommodations, we would also like to know if more detailed guidance from the OHRC is warranted. The OHRC has a mandate to address systemic discrimination in both government and private sectors, and has recently published its policy on creed. While that policy does give instruction on the overall framework for human rights accommodations, the OHRC could go further in consulting with health care institutions and care settings to establish protocols that prevent and respond to core barriers in this context.

Finally, the LCO recognizes that cultural competence within a multicultural society is not necessarily the same as cultural safety for First Nations, Inuit and Métis peoples. Certain individuals suggested that cultural safety can be used as a lens for all faiths and cultures, yet others said it is most applicable to the contemporary experiences of Indigenous peoples.

As with the LCO's review of palliative care in Indigenous communities more generally, we recognize that our project can only address cultural safety if there is a desire for us to do so within Ontario's Indigenous communities. Therefore, we will begin exploring what the LCO's role concerning cultural safety might possibly be through additional community engagement in early 2017.

# Ontario breaks jurisdictional barriers with vow for First Nations health care

G&M, Feb 13 2018

<https://www.theglobeandmail.com/news/politics/ontario-breaks-jurisdictional-barriers-with-vow-for-first-nations-health-care/article37973252/>

Christopher Katsarov/THE CANADIAN PRESS

[Gloria Galloway](#)

OTTAWA

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The Ontario government is preparing to announce that it is keeping a two-year-old promise to inject hundreds of millions of dollars into First Nations health care and that cash is now flowing to culturally appropriate initiatives including palliative care, primary care and mental wellness.

First Nations leaders say more money is still needed to bring the standard of care provided to their people to the level that is enjoyed by other Canadians. But they give credit to Ontario for breaking down jurisdictional barriers, both with the federal government and with Indigenous communities, to improve a system that has been rife with failure.

Perry Bellegarde, the National Chief of the Assembly of First Nations (AFN), said on Tuesday that Ontario has not fallen back on the excuse that Indigenous health care is a federal responsibility and is instead leading the way among provinces in spending to improve outcomes for First Nations people.

"They are basically going beyond the reserve boundaries and saying 'hey, health care is a right of everybody. We don't care if you live in Toronto or you live in Attawapiskat, we are going to provide resources to you,'" Mr. Bellegarde said.

Isadore Day, the Ontario Regional Chief of the AFN, said Ontario is also demonstrating that, despite its traditional control over health-care delivery within provincial boundaries, Indigenous communities in the province are being allowed to decide how their medical dollars are best spent.

"I am not overly excited about the level of investment," Mr. Day said. "I am optimistic that this is that first substantial step towards recognizing the relationship."

In May of 2016, the Ontario government said it would spend \$222-million over the next three years to enhance health care in First Nations communities. The plan was to provide culturally appropriate care delivered largely by Indigenous people themselves.

On Wednesday, at an AFN meeting in Toronto, Health Minister Eric Hoskins will announce that major aspects of that promise are being met.

In December, Ontario provided \$55,300 to each of the province's 133 First Nations to improve access to culturally appropriate home and community care.

The province has paid to create or expand 16 Indigenous primary care teams across the province.

It has trained hundreds of palliative care specialists who will work in First Nations communities.

It will soon announce the sites of 34 new Indigenous-led mental-health and wellness programs that will employ more than 100 mental-health workers and incorporate cultural teachings.

And, in the coming weeks, it will announce the establishment or expansion of 10 Indigenous-led healing and treatment centres.

These initiatives come at a time when the expected lifespan of First Nations people is five to seven years shorter than for non-aboriginal Canadians.

Mr. Hoskins said in an interview on Tuesday that health care is too important to let jurisdictional issues get in the way of delivery.

"You know the disparity in this province and across this country with regard to health outcomes when you compare First Nations communities and individuals and families with non-First Nations – the high rates of suicide, the high rates of diabetes and heart disease," he said. "So we all simply need to work together to reduce and eliminate those differences."

The way Ontario is doing that, he said, is to develop a system of health care for reserves that is planned and run by the First Nations themselves.

Alvin Fiddler, the Grand Chief of the Nishnawbe Aski Nation, which includes 49 First Nations in northwestern Ontario, said the province's efforts have been encouraging although they came as a direct response to a declaration of a state of emergency in health care that had been issued by his organization.

But there still needs to be an immediate investment in mental-health supports for Indigenous youth and children in Northern Ontario who are at risk of taking their own lives, Mr. Fiddler said. "We need to look at changing the current funding structure," he said, "so that we can maximize the resources to meet the communities where they are most needed."



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