Improving the Last Stages of Life

Multi-Faith Roundtable BACKGROUND DOCUMENT
Multi-faith Roundtable on Faith and Culture Needs in the Last Stages of Life

Wednesday, June 28, 2017
9:30 AM – 5:00 PM

Location: Ryerson Diversity Institute
55 Dundas Street West
Ted Rogers School of Management, 7th Floor, Commons (Rooms 1-148 and 1-150)

Contacts: If issues arise on the day of the roundtable, you can contact the following:
Ryan Fritsch 647-280-6747 or email rfritsch@lco-cdo.org
Amanda Rodrigues 647-518-5551 or email ARodrigues@lco-cdo.org

Directions

Subway
Dundas Station

Public Parking
Atrium on Bay

Enter through Edward Street, beside Red Lobster. Remember to obtain a parking pass from Amanda Rodrigues at the round table.
AGENDA

9:30 AM   Registration
*Light refreshments will be provided*

10:00    Welcoming Remarks
*Ryan Fritsch, Research Lawyer & Project Head, Law Commission of Ontario
Ruby Latif*

10:15    Group Scenario Activity 1

11:30    Discussion and Debrief of Activity 1

12:00 PM  Lunch

1:00    Group Scenario Activity 2

2:15    Discussion and Debrief of Activity 2

2:45    Break

3:00    Group Scenario Activity 3

4:15    Discussion and Debrief of Activity 3

4:45    Wrap Up and Next Steps
*Ryan Fritsch, Research Lawyer & Project Head, Law Commission of Ontario*
IMPROVING THE LAST STAGES OF LIFE: MULTI-FAITH ROUNDTABLE

Wednesday, June 28, 2017
10:00 AM – 5:00 PM

Registration begins at 9:30 AM
Lunch provided

This event is being organized in the context of the LCO’s project Improving the Last Stages of Life. For more information see:
http://www.lco-cdo.org/laststages

Join us to discuss your perspective on:

- the impact on the inclusion of faith, spirituality and culture in the last stages of life;
- integrating religious and cultural supports into quality care in the last stages of life;
- topics including:
  - treatment decisions and care planning;
  - resolving disputes;
  - accommodating faith needs and practices;
  - competing rights;
  - culturally sensitive care;
  - public and professional education; and
  - medical assistance in dying

RSVP by June 16, 2017
lawcommission@lco-cdo.org
416-650-8406

Invitation only. Limited spaces.
# Multi-faith Roundtable on Faith and Culture Needs in the Last Stages of Life: List of Participants

<table>
<thead>
<tr>
<th>Name</th>
<th>Organization/Role</th>
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<tbody>
<tr>
<td>Shaheen Azmi</td>
<td>Ontario Human Rights Commission</td>
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<tr>
<td>Joseph Chandrakanthan</td>
<td>Centre for Clinical Ethics</td>
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<tr>
<td>Ryan Fritsch</td>
<td>Research Lawyer, Law Commission of Ontario</td>
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<tr>
<td>Rabbi Baruch Frydman-Kohl</td>
<td>Beth Tzedec Congregation</td>
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<tr>
<td>Avvy Go</td>
<td>Metro Toronto Chinese &amp; Southeast Asian Legal Clinic</td>
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<tr>
<td>Rev. Canon Douglas Graydon</td>
<td>Anglican Diocese of Toronto</td>
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<tr>
<td>Omar Ha-Redeye</td>
<td>Fleet Street Law</td>
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<tr>
<td>Tracey Hand-Breckenridge</td>
<td>Cedar Creek Counselling</td>
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<tr>
<td>Sean Hillman</td>
<td>University of Toronto</td>
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<tr>
<td>Zul Kassamali</td>
<td>Toronto Area Interfaith Council</td>
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<tr>
<td>Lisa Kronenberg</td>
<td>Jewish Family and Child Service, Jewish Hospice Program</td>
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<tr>
<td>Ruby Latif</td>
<td>Milieu Strategy</td>
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<tr>
<td>Uday Lohakare</td>
<td>Hindu Federation</td>
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<tr>
<td>Christopher Lo</td>
<td>Cancer Clinical Research Unit, Princess Margaret Cancer Centre</td>
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<tr>
<td>Jeanette O'Leary</td>
<td>Shalom Village Nursing Home</td>
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<tr>
<td>Imam Abdul Hai Patel</td>
<td>Ontario Multifaith Council</td>
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<tr>
<td>Father Geoffrey Ready</td>
<td>Canadian Council of Churches Faith and Witness Commission</td>
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<tr>
<td>Professor Richard Schneider</td>
<td>York University</td>
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<tr>
<td>Professor Johanna Selles</td>
<td>University of Toronto</td>
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<tr>
<td>Catherine Starr</td>
<td>Campus Chaplains Association</td>
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<tr>
<td>Danielle Slump</td>
<td>University Health Network</td>
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<tr>
<td>Imam Ayman Taher</td>
<td>Hospital for Sick Children</td>
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<tr>
<td>Robert Tees</td>
<td>Niagara Health</td>
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<tr>
<td>Rev. Dr. John Young</td>
<td>The United Church of Canada</td>
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Improving the Last Stages of Life
Multifaith Roundtable on Faith and Spirituality

Organized in the context of the Law Commission’s project “Improving the Last Stages of Life” Project

SCENARIOS FOR DISCUSSION

➢ Preparing before the roundtable will facilitate your discussion with other participants.

These scenarios have been created to help start the conversation. Faith leaders may have been challenged with other similar situations, or different kinds of issues. We encourage you to think and reflect on these and to share them. We are also interested in hearing about the frameworks and beliefs that guide your approach to these kinds of dilemmas, and to hearing your suggestions about law reform measures that would be beneficial.

Please thoroughly read the introductory materials that were provided separate from this document, entitled “Background Documents”.

Reading the activity descriptions and excerpts from LCO’s prepared materials before the event will also help you to reflect on which experiences you would like to share.

Printed copies of this and the other material you’ve received will be provided at the event.
ACTIVITY 1

Identifying and Advising on Faith and Spiritual Needs

1. Context

Before answering the questions, please read the following scenarios and context:

Scenario 1: Biskane is receiving palliative care at her local hospital, and was recently moved to the ICU. Smoking, loud music, and the gathering of many family members are parts of Biskane’s spiritual healing beliefs, which include other aspects Biskane doesn’t observe. Some nurses have allowed the music and occasional visitors, while others do not. None of the nurses will permit smoking, citing hospital policy and the medical equipment. While there is a small multifaith prayer room down the hall, hospital policy is unclear about allowing smoking in there, and it’s too small to accommodate more than 2 or 3 people. Biskane is increasingly agitated that she’s unable to practice her faith, and has asked you to advocate on her behalf with whoever can help.

Scenario 2: Gerain is 86 years old and receiving end-of-life care at his home, with the assistance of a mobile team of health providers and personal support workers. The mobile team is only staffed by female personal support workers who are needed, in part, because Gerain is unable to bathe himself. Gerain has an honestly held belief that his faith, which is largely an oral tradition predicated on race, strictly prohibits a woman to bathe another man, his wife, or their children. Gerain states that he would rather be unclean and dirty than be cleansed by any woman. The mobile team is worried that failing to bathe Gerain may fall short of his best interests and a medical standard of care due to his recurring and life-threatening leg infections. Their suggestion is for Gerain to be admitted back into hospital, but this concerns him. He wishes to die at home so family can observe a post-mortem period of mourning, prayer and celebration with the body that would be impossible in a hospital setting. He also says the coroner better not interfere either.

The scenarios presented above raise issues about identifying and supporting faith, spiritual and cultural needs nearing the end of life. Ontario human rights law provides one approach to raising and discussing needs, options and accommodations. But spiritual adherents and health care providers alike may struggle with concerns about how to accommodate, when to accommodate, and how to balance rights that may appear to be competing.

Moreover, persons receiving care and their supporters may encounter challenges with faith, cultural and spiritual needs under health care consent law. How does the law balance competing factors that may include wishes, values and beliefs; best interests; family views; and the medical standard of care?
Patients may move from one care setting to the next (for example, from a private home to the ER and then back home before applying for long-term care). Often, it is difficult for users to find information and to understand what services they may be eligible for. Unfortunately, repeated transitions may also have negative outcomes on their outlook and health.

For this activity, please reflect on your experiences advising clients – whoever they may be – on issues surrounding identify and advising on faith and spiritual needs in the last stages of life.

2. Questions

With reference to your direct experience or what you’ve heard from others, please consider the following questions in your discussion.

- How do your beliefs approach these issues? Are there varying approaches within your faith, and how are those considered and discussed? Also, please consider your own beliefs and values, and how those factor in in these scenarios.
- It can be a challenge to identify a set of beliefs as a “creed” or “religion”, and to communicate this to a health service provider. How do you manage this? What are the barriers to having beliefs recognized or taken seriously, and what would help?
- What are some of the cultural and religious accommodations that have been requested to date? Which requests were successful and which were unsuccessful? What reasons were provided for why an accommodation could not be granted?
- How can end-of-life care support services account for patients who are atheist, agnostic, non-religious or inquisitive about spirituality?
- How can someone best ask questions to identify needs? What training would be beneficial for health care workers to receive to learn how to account for various cultural, religious and faith practices and beliefs? What steps should they then be prepared to take after the question has been asked?
- What is your familiarity with Ontario’s human rights system? Is it effective and helpful in resolving disputes, either formally or informally? Does it create a common framework for discussing issues of importance to your faith? How does it not?
- When is it best to identify and raise needs? What are some approaches and actions that can be taken for this to be better integrated into healthcare? What are some best practices around planning, and continuity of care?
- What are your insights or suggestions about law reform that would improve identifying and advising on faith?
ACTIVITY 2

Addressing and Resolving Disputes Nearing the End of Life

1. Context

For this activity, please reflect on what disputes you have encountered in the course of your work and what role you or other people played in resolving them.

Before answering the questions, please read the following scenarios and context:

Scenario 1: Sheena and a doctor are conflicted about whether her husband should be taken off life-support. In the doctor’s opinion, it is highly improbable that her husband will regain consciousness. As well, his declining health condition could require an emergency resuscitation event unlikely to benefit the patient. Sheena is her husband’s substitute decision maker. She and her husband are devout in their faith and she believes the withdrawal of treatment would violate the sanctity of life, as would withholding extraordinary measures. At a meeting the hospital asks Sheena to consent to their proposal, which she does not. They state that since she will not consent to the withdrawal of treatment, they will place a “do not resuscitate” order in her husband’s chart instead.

Scenario 2: Aliyah and her family members are life-long adherents to a faith with strong views about the sanctity of preserving life at all costs, as well as a belief in the importance of bodily integrity nearing and following death. Aliyah recently began thinking more about these issues since commencing palliative care in hospital. She raised her concerns with you as the hospital’s chaplain. She expressed concerns that the pain was becoming too much to bear, that maybe clinging to life wasn’t what she wanted, and that may be better to keep her body as whole as possible. She also said she had a similar talk with her son several days earlier. Shortly thereafter, you are visiting with Aliyah along with her son and members of the family. She very quickly goes into medical distress. Aliyah’s husband tells doctors to do everything they can to save Aliyah. Doctors then suggest that invasive surgery may help. Aliyah’s son speaks up and mentions her recent change of heart and expressed wishes and beliefs. Both the husband and son look to you for guidance.

The examples above are intended to reflect at least two of the many types of disputes between various individuals and institutions when conflicts about care in the last stages of life occur. The LCO has heard that conflicts may often occur about the withdrawal and withholding of treatment, determining a patient’s “best interests” as between SDMs and other family members, the difficulty in interpreting wishes, values and beliefs, and deciding whether to attempt significant medical
interventions for a frail individual. There are also competing concerns about medical futility and costs to the health care system, professional obligations to do no harm, and other such concerns.

Individuals and organizations access various avenues of recourse in these situations. Identifying faith and spiritual needs, communicating these needs, and reconciling competing needs may be part of the process. There are many ways to address the dispute. Persons may raise human rights concerns, including filing an application to the Human Rights Tribunal; they may make regulatory college complaints, seek out mediation, or follow informal procedures within the hospital.

2. Questions

- What dispute resolution mechanisms are best known to you, and most effective for the patient, their family, and/or the health service provider?
- What methods have you used to raise and communicate needs before conflict arises? What would a good institutional model be? Have you helped a facility design good policies and practices?
- How do you balance core tenants or beliefs with the individual views or practices of the dying person, or with limits to the flexibility of the health service provider? How do you find “constructive compromises”?
- Should faith and spiritual supporters be expected to have knowledge on health care consent law, informed consent, and other aspects of consent and capacity laws considering individuals may seek their guidance for end-of-life decisions?
- When should discussions on spirituality and religious beliefs and practices occur when receiving end-of-life care? Is this something that would be appropriate information to include in an advanced care plan or should this conversation occur when a person receives services? What is your opinion on incorporating a patient’s conception of “a good death” into advanced care planning? What role do you think advanced care planning should have in ensuring a patient can decide how they want to die in a way that aligns with their cultural and religious beliefs?
- Do you have any recommendations or ideas on how service providers could document patients’ and their families’ religious values and preferences? Should a structured approach be used, such as using standardized practice tools or advanced care planning documents? What kind of training or education can be provided on resolving disputes?
ACTIVITY 3

Expectations for Medical Assistance in Dying

1. Context

Before answering the questions, please read the following scenarios and context:

Scenario 1: Aisha is 86 years old and has lived with dementia for some time. Her family has noticed that her cognitive abilities and physical health are declining significantly, and she has considerable difficulty doing any daily tasks without help or considerable pain. Aisha had previously expressed that she does not want to live when she is no longer able to recognize and interact with her children. Aisha had previously expressed that food, liquids, and nutrition should be stopped in order to let her die. However, she is now accepting small amounts of cake when offered to her by a personal support worker, while refusing other foods. The family believes this is contrary to Aisha’s values and wants the facility to withhold providing nutrition. The care team believes Aisha’s preference for cake indicates she is making a conscious decision to eat, and intend to continue providing Aisha with nourishment.

Scenario 2: St. James is a religious hospital in a remote part of northern Ontario. It receives a mix of private and public funding. Lee has advanced cancer and is receiving palliative care at the hospital. According to his oncologist, Lee suffers from intractable symptoms. Lee is a follower of the hospital’s faith and practice and wishes to continue his care in that setting. But contrary to the generally accepted teaching of the faith, Lee asks if he can initiate the process of medical assistance in dying. His oncologist is willing to assist. St. James Hospital objects to the provision of medical assistance in dying on the premises or by health care providers working within its walls, and also doesn’t want to assist with referrals. St. James is also the only facility in the area with a pharmacy, and will not provide drugs necessary for assisted dying.

These final scenarios come from our knowledge of various questions being asked about how medical assistance in dying will be implemented in Ontario.

Many individuals may have questions about how medical assistance in dying impacts them as patients, residents in long-term care homes or recipients of home care. For example, they may have concerns about eligibility, capacity requirements, advance care planning, safeguards against abuse and avenues of recourse if their requests are denied.
On the other hand, health care providers and facilities may have further concerns, for instance, about how medical assistance in dying will be delivered by health teams across various care settings or the procedures to follow when providers (or institutions) conscientiously object. They may also have institutionally held beliefs, concerns about liability, and conflicting instructions from substitute decision makers or patients of questionable capacity.

For this activity, please reflect on what experiences you’ve had in this area to date, if any, as well as what you’ve heard. As with the previous activities, the focus should be on your role as legal professionals within this developing area.

2. Questions

- What formal and informal dispute resolution mechanisms exist when patients and their families, or substitute decision-makers have faith, cultural, and or religious beliefs that conflict with the existing services health care facilities provide?
- Are you able to comment on the balance between the wishes of the individual and the goals of the institution where they differ, as now in MAID?
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Preparing before the roundtable will facilitate your discussion with other participants.

This document provides you with summary information on relevant documents and potential issues for our discussion. Please read through it in advance of the event. For endnotes, please see the original documents at www.lco-cdo.org/laststages.

We have also provided a separate document for your preparations. It contains a list of questions and contextual information and is entitled, “Scenarios”. This document will be sent to you on Monday, June 26.
I. Roundtable Objectives and Activities

➢ Please read this document and accompanying materials to prepare for the event.

The Law Commission of Ontario (LCO) and partners are pleased to invite you to this unique opportunity. The LCO is leading a project that considers the role of the law in improving the quality of life for persons who are dying and those who support them, called Improving the Last Stages of Life.

As part of the project, we are co-hosting this multi-faith roundtable on the issues particular to faith and cultural needs in the last stages of life.

The purpose of the roundtable is to bring together a broad diversity of faith leaders, spiritual advisers and chaplains, academics, legal advocates, and health practitioners in conversation about these issues, with the goal of identifying issues and practical recommendations for law reform.

The roundtable is a workshop-style event for persons who feel comfortable sharing their experiences. Your participation will involve intensive discussion in small groups guided by questions contained in your materials. There will be three activities throughout the day that center around the following themes:

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<td>1. Scenario 1: Identifying and Advising on Faith and Spiritual Needs</td>
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<td>2. Scenario 2: Addressing and Resolving Conflict Nearing the End of Life</td>
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Results of the roundtable will be incorporated into an interim report for the Law Commission’s project and will be taken into account when we consider possible recommendations for reform. They will also be summarized in a brief report that will publicly disseminated.
II. Law Commission of Ontario’s Project

A. Project scope and objectives

The LCO’s Improving the Last Stages of Life project considers how the law shapes the rights, choices, and quality of life for persons who are dying and those who support them. The project seeks to address the experiences of everyone involved in the dying process, including: individuals, caregivers and other family and friends, health care institutions and professionals, government, other professionals and community organizations. Our goal is to hear from these groups to better identify and recommend law reforms that are concrete, precise, and responsive to the experience of persons in the last stages of life. It is important to emphasize that this project does not consider the appropriateness or legality of any particular medical procedure or medical model of care.

The province’s rich diversity in faith and cultural communities, and many other rights-seeking groups, also has a significant role to play in this ongoing shift. Questions about accommodations, culturally-appropriate and personalized care are at the forefront of our minds when determining what “quality care” means.

As a law reform agency, the LCO’s work focuses on the law’s potential to strengthen equality in access to quality care for all Ontarians.

Our project considers the unique needs of individuals and communities that experience challenges accessing care in the last stages of life due to factors, such as age, LGBTQ identity, income level, homelessness, place of residence and cultural identity. It also addresses a number of legal issues that we have been told require clarification, simplification or better implementation in practice.

To the extent that our project seeks to reflect diverse circumstances and needs, it is broad and inclusive. However, the issues that we are addressing for the purposes of law reform are quite precisely defined. We summarize the issues to be addressed in the project, that are related to faith and cultural needs, below.

B. Areas for law reform

This is an area of the law that is rapidly changing. The governments of Canada and Ontario have several ongoing initiatives that impact the LCO’s project, including Ontario’s development of a
provincial strategy on palliative care; the Province’s restructuring of the home and community, primary care and public health systems; and both jurisdictions’ development of frameworks to regulate medical assistance in dying. The LCO’s project doesn’t duplicate government work in these areas. We look at issues in addition to those that are currently the subject of enacted or proposed legislation.

The LCO’s project considers issues that go beyond these government initiatives. We examine a number of legal issues that fall outside their mandates as well as “gaps” in their ongoing efforts. Examples of areas that stakeholders informed us might benefit from law reform include,

- **Equitable care for all.** Social determinants such as age, disability, LGBTQ identity, Indigenous identity, income level, place of residence, mental health, religious beliefs and culture can strongly affect the setting, type and quality of care that Ontarians receive. The LCO is looking at these communities and considering issues like access and accommodation.

- **Ontario’s laws and programs.** Laws and programs in Ontario shape the approach to issues like palliative care; health care decision making, planning, and substitute consent; medical assistance in dying; the “public health” approach to palliative care; and how end of life impacts employment rights, caregiver benefits, insurance coverage, and rights in long-term care and retirement homes.

- **End-of-life challenges.** The LCO is considering a broad range of specific legal and policy challenges that arise at the end of life, including issues regarding autonomy, self-determination, beneficence (and maleficence) in care, and safeguards against abuse. These arise in several specific contexts, including the legal framework for, and public understanding of, consent and advance care planning; decision-making authority over life-sustaining practices, including withdrawal and withholding of treatment, CPR, and nutrition; palliative sedation therapy; managing planned deaths at home; the experience of supporting professionals; and accommodation and supports for faith and cultural communities.

- **Resolving disputes.** The LCO takes a look at assistance with the law, including navigation, dispute resolution and public legal education.

Beyond the above examples, there are many other issues for the project. One general issue concerns the responsibilities of professionals working in this area (e.g., health care providers, lawyers) and related needs for information, education and guidance.
With respect to faith and cultural needs, the LCO’s project asks

“What approaches are best suited to address barriers, accommodations and supports to better integrate faith, cultural and spiritual practices into care nearing the end of life?”

There are multiple strategies that could be used to improve culturally competent and safe care in Ontario. Possible solutions that service providers and community members spoke to the LCO about include creating educational tools for cultural competence and safety. 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. 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.

Our interim report will summarize observations made during this roundtable with a view to making appropriate recommendations for our final report.

III. Relevant Legal Frameworks

A. 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. 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”. Under the Canada Health Act (CHA), the federal government transfers funds to provinces that provide health care services through insurance plans, such as OHIP. Service delivery largely rests with the provinces.

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”. In several cases, the Supreme Court has identified what types of government activities violate the Charter, most notably under s.15 (equality) and s.7 (life, liberty and security of the person).
Important lessons from Supreme Court cases include the following:

- Publicly funded health care services must be provided in a non-discriminatory manner. Governments may be required to take positive steps to accommodate persons up to the point of “undue hardship” (see: Eldridge v. British Columbia).⁵

- Equality protections do not extend to discrimination claims relating to services that governments have chosen not to include the medicare basket of services (see: Auton v. British Columbia)⁶

- Criminal sanctions against medical practices cannot deprive individuals of fundamental rights of life, liberty and security of the person (see: Carter v. Canada; R. v. Parker; R. v. Morgentaler)⁷

- Section 7 of the Charter engages principles of autonomy, dignity, quality of life and the right to make decisions about one’s bodily integrity and medical care (see: Carter v. Canada)

More specifically, in Carter v. Canada, the Supreme Court of Canada held that the criminal prohibition against medical assistance in dying in certain circumstances violates s.7 of the Charter. The Court also held that “a physician’s decision to participate in assisted dying is a matter of conscience and, in some cases, religious belief.... we underline that the Charter rights of patients and physicians will need to be reconciled”.⁸

Constitutional rights in the context of health care decision-making have also been asserted on Aboriginal and religious grounds.⁹ The cases addressing those rights involve complex issues about the interaction of the Constitution with provincial decision-making laws. Faith and cultural beliefs and practices may be taken into account in end-of-life decision making consistent with the Health Care Consent Act, 1996, including decisions about the refusal to be treated and withdrawal of life-sustaining treatment.¹⁰

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.¹¹ The LCO is aware of legal professionals and community advocates who argue for a national right to palliative care under ss.7 and 15.¹²

B. Provincial human rights

The Ontario Human Rights Code (Code) provides equality rights 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. 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.

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. Compliance may demand accommodations that meet the needs of disadvantaged persons up to the point of undue hardship.

The Code is inspired by principles of inherent dignity, the worth of every person and participation in community life. 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.

In the context of this project, the LCO is aware that human rights concerns arise with respect to,

- the type and quality of care provided within facilities – such as hospitals, hospices and long-term care homes – to persons with specific end-of-life beliefs and practices
- equality in access to publicly funded services and supports, regardless of factors such as age, creed, disability and LGBTQ identity
- health care providers’ concerns that religious or conscientious objections to provide medical assistance in dying be reconciled with patients’ rights.

C. Health care decision-making

Capacity and decision-making laws are inseparable from policy debates about rights nearing the end of life. Together, the Health Care Consent Act, 1996 and Substitute Decisions Act, 1992 govern informed consent, advance care planning and substitute decision-making in Ontario. 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.

The HCCA empowers individuals to make decisions for themselves when capable. It also enables them to express wishes, values and beliefs that substitute decision-makers (SDM) must take into account when making decisions on their behalf, should they become incapable.
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.\(^{23}\)

The LCO has a separate, ongoing project that comprehensively reviewed the HCCA and SDA, called *Legal Capacity, Decision-Making and Guardianship*. That project is now complete, and the final report with recommendations is available on the LCO’s website.

This current project on the last stages of life builds on our findings in that other project, and we do not revisit the issues address there. Instead, we examine narrow concerns that stakeholders brought to our attention because they frequently arise with respect to end-of-life decision making.

The LCO’s project also considers the impacts of suffering (arising from chronic illness, end-of-life pain and symptoms, or medications) on decision-making capacity and on undertaking capacity assessments.\(^{24}\) Therefore, if you have observations on that topic, we would be glad to hear them.

➢ To access reports and other documents from the LCO’s project on Legal Capacity, Decision-Making and Guardianship, please visit our website at [http://www.lco-cdo.org/](http://www.lco-cdo.org/).

**D. Palliative and end-of-life care**

Palliative care has grown from a grassroots movement led by dedicated health care providers and community organizations to an accepted model of care in Ontario’s health care system. Definitions of palliative and end-of-life care are provided in the glossary at Appendix I.

Ontario’s institutional framework for delivering care in the last stages of life 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*.\(^{25}\) Unlike Quebec, British Columbia, Alberta and other jurisdictions with strategies to incorporate palliative care across the system, Ontario is currently formulating its provincial strategy.\(^{26}\)

As a result of its origins as a grassroots movement, palliative care services and supports in Ontario tend to be situated where advocates were located over time. It is generally accepted that access to palliative care is, therefore, inconsistent across the province’s regions and care settings. Yet individuals who are dying should be able to access quality care wherever they find themselves.
Relevant care settings for persons in the last stages of life include the following:

- long-term care homes
- retirement homes
- hospitals
- residential hospices
- day programs.

Challenges accessing palliative care in Ontario are well-documented in recent reports, such as the Auditor General of Ontario’s report released in December 2015. The Ontario government has made commitments to improve palliative care in the province through a number of initiatives and increased investments. Notably, the government has mandated an MPP, John Fraser, to oversee the development of a palliative care strategy and the expansion of residential hospices.

Ontario also inaugurated a provincial-level “network” that brings together various partners to drive implementation of consistent quality palliative care across the province, called the Ontario Palliative Care Network (OPCN). The OPCN is an organized partnership of community stakeholders, health service providers and health system planners, accountable for the development of a coordinated, standardized approach to the delivery of palliative care.

The LCO has committed to avoid overlap with the above ongoing efforts in this area. Consequently our project focuses on “gaps” in current planning. In particular, we address concerns about

- equality in access to care for communities with special needs, including persons with disabilities, LGBTQ identity, serious cognitive and physical frailties, cultural beliefs and practices, and Aboriginal peoples
- benefits for caregivers and other family and friends
- informational and advocacy supports for navigating transitions between care settings (e.g., from hospital to long-term care)
- whether palliative sedation should be regulated and how (as it is currently not regulated in Ontario)

In this roundtable event, we would be pleased to hear about any experiences you may have had facilitating the provision or receipt of palliative and end-of-life care in a variety of care settings.
E. Medical assistance in dying

In the *Carter* decision, the Supreme Court of Canada found that criminal sanctions against physician assisted dying violate the *Charter* where it would support a person in the following circumstances:

...[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.\(^{30}\)

The Supreme Court chose to “make no pronouncement on other situations where physician-assisted dying might be sought”.\(^{31}\) Furthermore, the Court suspended its declaration of invalidity for 12 months, granting the federal government a deadline of February 2016 to respond.\(^{32}\)

In response to the decision, several expert reports were commissioned and delivered at the federal and provincial levels over the course of 2015 and 2016.\(^{33}\) These reports made various – sometimes congruent, sometimes conflicting – findings on regulating medical assistance in dying.

Following a change in government at the federal level, the new Liberal government was granted a request to extend the suspension of the Supreme Court’s declaration of invalidity, which expired on June 6, 2016.\(^{34}\) As of June 6, 2016, physician assisted dying is a legal health care service in Canada.

When the Supreme Court extended the declaration of invalidity, it also granted an exemption from criminal liability to individuals who wished to exercise their rights during the extension through an application to a superior court.\(^{35}\) The Ontario Superior Court of Justice issued a Practice Advisory to guide applications for judicial authorization of medical assistance in dying for the interim period. Among other guidance, this Practice Advisory suggests that applicants obtain affidavits from the attending physician, the physician proposed to assist death, and a consulting psychiatrist.\(^{36}\)

The LCO is aware that the court process has been used to access medical assistance in dying in at least 7 cases in Ontario.

In April 2016, the federal Bill C-14, *An Act to Amend the Criminal Code and to Make Related Amendments to Other Acts (Medical Assistance in Dying)*, was introduced in the House of Commons.\(^{37}\) The Bill, as amended, passed the third reading stage and was sent to the Senate. It
is being amended by the Senate and will, eventually, need to be passed again by the House of Commons. It must be passed by both chambers in the same form before becoming a law.\textsuperscript{38}

Given that physician assisted dying became legal on June 6, the \textbf{Ontario Ministry of the Attorney General and Ministry of Health and Long-Term Care} issued a joint statement with information on how it is to be provided in the immediate term. Key aspects of their announcement include the following:

- Patients who wish to access medical assistance in dying should talk to their health care provider
- Health care providers should consult their regulatory colleges about any rules, guidelines or practices
- Ontario will establish a referral service to support physicians in making an effective referral for consultation and assessment
- Patients and health care providers are encouraged to seek further clarity about how the \textit{Carter} decision applies to their particular circumstances by bringing an application to the Ontario Superior Court of Justice (although this is not required)
- Ontario will continue to monitor developments at the federal level and will also pursue amendments to provincial legislation to further support implementation.\textsuperscript{39}

The \textbf{College of Physicians and Surgeons of Ontario} (CPSO) disseminated a policy on \textit{Physician-Assisted Death} as interim guidance, prior to the introduction of Bill C-14.\textsuperscript{40} The CPSO policy addresses the \textit{Carter} criteria, including issues surrounding consent, what constitutes a “grievous and irremediable” condition and intolerable suffering, among other criteria. The CPSO also developed a draft policy on \textit{Medical Assistance in Dying} to reflect the proposed federal legislation. However, the latter will be finalized whenever the federal legislation becomes law.\textsuperscript{41}

Because the \textit{Carter} decision only considered “physician” assisted dying and not the role of other health care providers, the \textbf{College of Nurses of Ontario} has issued a statement that “If clients are seeking information about medical assistance in dying, nurses should refer them to a physician”.\textsuperscript{42} Among other guidance, the \textbf{Ontario College of Pharmacists} issued a document stating “the College recommends that a pharmacist or pharmacy technician consult with their own legal counsel before providing services to support a physician’s prescription for physician-assisted death”.\textsuperscript{43}
It is important to note that in the absence of federal or provincial legislation, the constitutional parameters set by the Supreme Court for eligibility are instructive. Ontario Superior Court decisions should provide guidance to legal counsel and others on the application of the Carter decision.\(^{44}\)

For instance, based on the Carter decision, the Ontario Superior Court of Justice has found that persons need not have a terminal or life-threatening illness to access physician assisted dying.\(^{45}\) However, it noted that whether a person’s condition will end in death remains relevant as does the remoteness of death and duration of suffering. In Justice Perell’s words,

The imminence of death may not be determinative, but it is something to consider in determining whether a person has a grievous and irremediable medical condition including an illness, disease or disability.

In determining whether a person satisfies the criteria for a physician-assisted death, the proximity or remoteness of death and the duration of suffering are relevant factors that must be considered in the unique and special circumstances of any applicant for a physician-assisted death. Each application is personal to the applicant and the court must consider the applicant’s unique and special circumstances.\(^{46}\)

As many participants in this roundtable event will be aware, one of the main areas under discussion in Parliament is whether a person’s death must be “reasonably foreseeable” for it to qualify as a grievous and irremediable condition (as proposed in the original Bill C-14).

The LCO is aware of further points of contention at the federal and provincial levels that include whether advance requests will be permitted, whether children will access medical assistance in dying, and what safeguards will be put in place to protect persons who may be incapable or otherwise vulnerable to the undue influence of others.

At this roundtable, we are interested in knowing what practical and ethical challenges this changing landscape poses to members of the legal profession.

F. Dispute resolution

Death, dying and bereavement are highly emotional and important experiences for everyone involved – patients, family, friends and health care providers, alike. It is not surprising then that disputes arise in these circumstances and, when they do, that disputes can have serious repercussions on everyone’s well-being.
Conflicts may revolve around health care decision-making, eligibility for services or complaints about the quality of care being provided. There are several avenues of recourse to resolve such conflicts in Ontario. The our knowledge, these include

- informal policies and practices within health care facilities
- administrative complaints to regulatory colleges or designated review committees
- applications to the Consent and Capacity Board (CCB)
- applications for review to the health boards (notably, the Health Professions Appeal and Review Board)
- complaints to the Patient Ombudsman

The LCO’s project considers whether additional policies and practices could be introduced to either preempt or resolve disputes in the place where individuals are located prior to engaging administrative processes.

Although there are informal policies and practices within health care facilities, as noted above, the LCO has heard that these are not always engaged, they may inconsistent, and patients and family members may not feel that facilitators such as ethicists, lawyers or other health care providers represent their interests.

The Patient Ombudsman recently became operational with the first appointment to the role in December 2015. The Patient Ombudsman’s responsibilities include responding to complaints from patients and caregivers about the patient’s health care experience at a health sector organization, which includes hospitals, long-term care homes and centres for coordinating home care.

It is possible that the Patient Ombudsman might provide a means to fill the gap between informal complaints to health facilities and administrative procedures. However, it is not clear at this time what formal and informal avenues of recourse patients and caregivers will be required to access before engaging the Patient Ombudsman, including the CCB, regulatory colleges and health boards.

In this roundtable, we would like to hear about how you have been involved in resolving disputes in this area as legal professionals, and what practical and ethical challenges you face.

The following is an excerpt from the LCO’s Discussion Paper on the Last Stages of Life, released in May 2017. For the full report, please see www.lco-cdo.org/laststages.

1. Introduction

Palliative care’s holistic philosophy was originally conceived by Cicely Saunders, a deeply religious person who sought to integrate pain management with community environments and spiritual engagement. As a result, “Religion has had a profound role in shaping the development of the international hospice movement”, as has respect for community membership.

Saunders’ use of the term “spiritual” was connected to her own religious traditions. It preceded contemporary usage of the same term to mean a value system apart from, or at least not necessarily, connected to religion. In this section, we explore the relationship between concepts including “religion”, “faith”, “spirituality”, and “culture” to understand how they overlap and differ before beginning our review.

Following our discussion of terminology, we consider the significance of faith and culture to quality care in the last stages of life. We then review Ontario’s existing legal frameworks for faith and cultural rights. Finally, we analyze challenges and opportunities for reform.

Much of this section relies on a report the LCO commissioned from external experts. The paper, Integrating Religious and Cultural Supports into Quality Care in the Last Stages of Life in Ontario, presents new qualitative information that the authors gathered in consultation with health care providers, faith leaders and representatives of cultural communities in Ontario.

➢ To read the full research paper commissioned by the LCO on faith and cultural issues, please visit our website at www.lco-cdo.org.

2. Significance of faith and culture nearing the end of life

i. Defining faith and culture

The LCO has chosen to use the terms “faith” and “culture” in our report for their broad scope and regular usage among stakeholders whom we consulted. We intended these terms to be inclusive of other words relevant to the issues the project reviews such as “religion”, “ethnicity”, “ancestry” and “language”. We also acknowledge they might overlap with additional social concepts such as “race”.
The Ontario Human Rights Commission (OHRC) recognizes that individuals see themselves and others as a “unique combination of identities”\(^{54}\). Within the human rights system, there are distinctive attributes associated with each ground for equality (e.g., sex, age, race), but people also have intersecting identities that may not be captured by one ground. If individuals face discrimination, ideas about identity – such as faith and culture – are not easily separable.

In considering issues related to faith, it is useful to reference the OHRC’s definition of “creed”, which includes religious traditions and other “belief systems that, like religion, substantively influence a person’s identity, worldview and way of life”.\(^{55}\) The OHRC explains that a creed

- is sincerely, freely and deeply held
- is integrally linked to a person’s identity, self-definition and fulfilment
- is a particular and comprehensive, overarching system of belief that governs one’s conduct and practices
- addresses ultimate questions of human existence, including ideas about life, purpose, death, and the existence or non-existence of a Creator and/or a higher or different order of existence
- has some “nexus” or connection to an organization or community that professes a shared system of belief.\(^{56}\)

Approaches to the concept of “creed” remain controversial. The LCO is sensitive to apprehensions about the OHRC’s definition of “creed” as being overly broad because its capacious scope includes social movements that are not at all akin to religion (for instance, worshipping extraterrestrials).\(^{57}\) From a practical perspective, an overly broad definition could confuse or dilute attempts to delineate religious accommodations. During the LCO’s preliminary consultations, we heard considerable confusion about how to appropriately apply this definition in this context.

At the same time, however, the LCO values the OHRC’s definition for its potential to encompass variations within traditions and between individual and group beliefs. The OHRC’s definition also validates beliefs and practices that are intimately tied to history, tradition, ethnicity and culture, such as Indigenous spirituality.

“Cultural competence” is an established term in the health care context. Culture is not an enumerated ground under the *Human Rights Code* or the *Charter*. However, there are linkages to grounds enumerated under the Code such as ancestry, place of origin, ethnic origin, race and creed. The possible overlap between these concepts is evident in the following definition of culture:
A way of life common to a group of people, including a collection of beliefs and attitudes, shared understandings, and patterns of behavior that allow those people to live together in relative harmony, but that set them apart from other peoples. These practices also produce behavior that falls within a range of variation the members consider proper and acceptable.58

In this discussion paper, we write about faith and culture together, and distinguish them where appropriate. For instance, a newcomer to Canada may belong to a cultural community but hold no faith beliefs. Later in this section, we explain that the Charter protects freedom of religion under a separate provision from equality.59 Equality rights extend to religion, but they also protect individuals and groups that may not be religious (or may not have been discriminated against as a result of religion). The legal tests to assert a rights claim under these Charter provisions differs.

<table>
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<tr>
<th>A Note on “Spirituality”</th>
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<tr>
<td>Spirituality may refer to an individual's religious experience. However, in contemporary usage, the word often does not refer to experiences with a single formal religious tradition. People who are atheist or agnostic may consider themselves spiritual as well.60</td>
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<td>In present-day palliative care, psychosocial “spiritual” supports are not usually associated with religion. They may be provided by health care providers, chaplains and social workers who lead conversations on existential issues about meaning and loss.61 Understood in this way, the application of legal frameworks to spiritual rights and accommodations is ambiguous.</td>
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ii. How faith and cultural affect access to quality care

*Spiritual care and faith based care is somebody's way of life. It is how they know themselves and how they known how to interact with others... In the medical world we say we are providing total care, you know, we are providing holistic care. It is not holistic, if spiritual and faith based care [are not there] and particularly... when you are not looking at the culture that... the client is telling us he is a part of or feels strongly [about].*62

— Registered nurse

Faith and culture are integral to attitudes about care nearing the end of life and perceptions of quality in health care services. While Ontario strives to improve equitable and high quality palliative care, it should consider strengthening services that reflect deeply held patient values and wishes for community engagement. As the Fraser Report explains, Ontarians have pronounced views “about the importance of ensuring that all patients have access to culturally appropriate and safe palliative and end-of-life care”.63
Perhaps it is because faith and culture have profound meaning at the end of life that disagreements – even misunderstandings – about suitable care may lead to conflict. Nearly each person whom the LCO has spoken to referenced faith and culture as factors leading to disputes between patients, SDMs and health care providers. Much of the case law that affirms decision-making rights in this context also results from disputes between health care providers and faith adherents. Thus, in addition to promoting experiences of good care, avoiding disputes is a material rationale for integrating faith and culture into the health system.

These disputes may arise in a wide variety of ways. Faith may shape a decision to request or reject a particular treatment contrary to the recommendation of the health provider. In cases where the patient has become legally incapable, disputes have arisen as to how the patient’s faith should affect the interpretation of their advance care planning documents. These disputes may be particularly challenging where individual beliefs do not cleanly conform with institutional orthodoxy. In some situations, a patient’s faith may lead to a request to have services provided by an individual of a particular gender or sexual orientation. Or, health providers may have conscientious objections to providing a requested treatment.

Some of these disputes raise concerns about competing rights. For example, a patient’s faith-based request to receive treatment or services only from professionals of a particular gender, or not to receive services from persons who are LGBTQ, may have a discriminatory effect on the service provider. The Ontario Human Rights Commission has explored these issues in its Policy on Competing Rights. These issues are discussed at more length in Chapter 6. F.

The LCO commissioned paper explains these two interrelated ways in which faith and culture affect access to quality care:

A recurring theme of our research [is] an acceptance and acknowledgement of the importance of faith and cultural beliefs as vital components in shaping how Ontarians choose and direct their care at the end of life. However, these beliefs also act as unexpected barriers to health care providers providing the best services for Ontarians as they approach death.

Within the confines of this discussion paper, the LCO cannot describe examples of beliefs and practices among Ontario’s diverse communities without being reductive. We recommend sources that readers can access for that information at the end of this part.

Below, we simply highlight general ways in which faith and culture influence care for the dying. Our purpose is to identify moments when heightened attention to faith and culture is due:
1. **Treatment decisions**: Patients and SDMs may take faith and cultural beliefs into account when making decisions about life-sustaining treatments. Some belief systems are uncomfortable with mainstream health services; others maintain that life support should be provided indefinitely until a person dies. Between the two, there is a spectrum of beliefs about withholding and withdrawing life support, medical assistance in dying and the receipt of non-traditional treatment.\(^67\)

2. **Practices during illness**: Faith and cultural communities may exercise meaningful practices during illness, such as prayer and ceremonies. Practices are expressive and may require adaptive physical environments that can accommodate singing and music, smoke, prostration and visitations from community members that may exceed standardized allowances.\(^68\) Practices may occur at key junctures in the illness trajectory that could require adjustments to procedural routine.

3. **Significant community figures**: Community figures may embody a sense of history and collective experience. For instance, elderly persons who survived past atrocities emanating from hate and discrimination can hold special significance for community members.\(^69\) Family and community members might expect these figures to receive particularly respectful treatment.

4. **Care for the deceased**: Caring for the deceased may involve a variety of practices, ranging from prayer to tending to the body and burial ceremonies. There may be a critical order for the succession of practices. Community members may also request to be involved in physical after-death care, and to exclude health care providers. Keeping the deceased’s body “whole” is a central belief for many faiths and cultures, which organ donation or autopsies might offend.\(^70\)

The above description of moments when faith and culture are engaged during the dying process is admittedly limited. Other recurring themes that the LCO heard about include food preferences, language needs and continued contact with faith and cultural peers, especially in long-term care homes.

For detailed examples of common beliefs and practices among Ontario’s diverse communities, readers might consider the following sources:

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<th>Summary Titles</th>
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<tr>
<td>Ruby Latif, Omar Ha-Redeye &amp; Kashif Pirzada, <em>Integrating Religious and Cultural Supports into Quality Care in the Last Stages of Life in Ontario</em> (2016)(^71)</td>
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<tr>
<td>Harold Coward &amp; Kelli Stajduhar, eds, <em>Religious Understandings of a Good Death in Hospice Palliative Care</em> (2012)(^72)</td>
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</table>
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.75

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.76 Health care that does not respond to these factors has been considered to generate “risks” to security.77

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.78 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.79

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.80

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.  

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.

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.

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. 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. It guarantees individuals and groups freedom from government activity that interferes with their sincerely held religious beliefs and related practices. 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. Most recently, religious beliefs have been generally characterized as implicit in “best interests” tests that factor in values and beliefs. 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. However, even Justices who found there to be a rights violation have concluded it was justifiable as a reasonable limit.

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”. The Code promotes equality and non-discrimination in
requiring that individuals and groups “may equally access, benefit from, and are equally treated”. 92 Under the Code, health care providers and facilities have a duty to accommodate sincerely held beliefs and practices to the point of undue hardship. 93

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. 94

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”. 95

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. 96 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. 97 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. 98 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. 99

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. 100

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.\textsuperscript{101}

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.

\textbf{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 \textit{Long-Term Care Homes Act, 2007} and \textit{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.\textsuperscript{102} In developing a plan of care or services, providers must ensure that these factors are incorporated or considered.\textsuperscript{103} Moreover, in assisting a resident with placement in a long-term care home, coordinators must consider faith and cultural preferences.\textsuperscript{104}

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 \textit{Human Rights Code} for special interest institutions.\textsuperscript{105} 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”.\textsuperscript{106} 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 \textit{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”.\textsuperscript{107} 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.  

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 RNAO guidelines on cultural competence and the CPSO policies on end of life and human rights. 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.

Currently in hospitals, there are few formal policies on faith and cultural issues. 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. Many facilities do not, however, have full-time chaplains and most are Christian, creating inequalities across religious traditions. 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.

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.” The piecemeal approach to integrating cultural competence into care settings has led to inconsistencies in services and, overall, inequalities in access.

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. ¹¹⁷

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.

5. Questions for discussion

15. What approaches are best suited to address barriers, accommodations and supports to better integrate faith, cultural and spiritual practices into care nearing the end of life?
V. Key Terms and Concepts: Excerpt from LCO Commissioned Paper

The following is an excerpt from the LCO research paper, “Integrating Religious and Cultural Supports into Quality Care in the Last Stages of Life in Ontario.” The paper was commissioned by the Law Commission of Ontario and written by Omar Ha-Redeye, Ruby Latif, and Kashif Pirzada. For the full report, please see www.lco-cdo.org/laststages.
INTEGRATING RELIGIOUS AND CULTURAL SUPPORTS INTO QUALITY CARE IN THE LAST STAGES OF LIFE IN ONTARIO

Improving the Last Stages of Life

April 2017

Commissioned by the Law Commission of Ontario

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The LCO commissioned this paper to provide background research for its “Improving the Last Stages of Life” project. The views expressed in this paper do not necessarily reflect the views of the LCO.
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Law Commission of Ontario 29 June 2017
II. KEY TERMS AND CONCEPTS

Prevalent in the discussion of end-of-life care are a number of concepts and terms that may have different and deeply personal meanings to each individual. A brief explanation of key concepts and terms is provided below.

A. Last Stages of Life, Palliative Care, and End-of-Life Care

The Law Commission of Ontario’s (LCO) project, Improving the Last Stages of Life, considers the role of the law in fostering quality of life for persons who are dying and those who support them. Their goal is to recommend law reforms that are concrete, precise, and responsive to the experience of Ontarians in the last stages of life.

The “last stages of life” is the broad and inclusive term used by the LCO to capture this experience of dying as a process or a continuum of events, whether as a result of terminal illness, chronic conditions or serious frailties that could progress until the end of life. Some such persons may have little time left to live, while others may transition through the dying process for an extended period of years. The LCO’s definition of “last stages of life” is unique. Their objective in selecting this term is to distinguish the experience of persons who are dying – as a particular stage in life – from established models of care that may be beneficial during the dying process, most notably palliative and end-of-life care.

This broad and inclusive term contrasts with the specificity of “palliative care” and “end-of-life care.” The World Health Organization provides the following definition of palliative care:

Palliative care is a care regimen that aims to improve the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

Palliative care has a number of elements and individual patient care may encompass all or only a select number of the following:

- relief from pain and other distressing symptoms;
- affirmation of life and the regard of dying as a normal process;
- neither hastening nor postponing death;
- integration of the psychological and spiritual aspects of patient care;
- provision of a support system to help patients live as actively as possible until death;
- provision of a support system to help the family cope during the patient’s illness and in their own bereavement;
- a team approach to address the needs of patients and their families, including bereavement counseling, if indicated;
possibly used in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and including those investigations needed to better understand and manage distressing clinical complications.

This distinguishes “palliative care” from “end-of-life care.” End-of-life care refers to care provided to persons whose death is likely imminent. Persons at the end of life are typically in the advanced stages of a life-limiting condition, are in their last weeks or days of life and may require intensive services. The terms “end-of-life care” and “palliative care” are often used synonymously in the literature; however, they are distinguishable. End-of-life care is only one aspect of palliative care. Palliative care is a philosophy of care and it encompasses a broader range of treatments and accompaniments throughout the dying process.

For the purposes of this paper, the authors will rely on the “last stages of life” as the umbrella term inclusive of the experiences of persons who are dying, distinguishing “palliative” and “end-of-life” care where relevant to the discussion.

B. Faith and Creed

The Oxford English Dictionary provides a simple definition of faith as either: a) the strong belief in God or the doctrines of a religion, based on spiritual apprehension rather than proof, or b) a system of religious belief, as in the “Christian Faith.” For the purposes of this paper, the authors invoke “faith” as encompassing both aspects of this definition.

This inclusive definition of “faith” is additionally read to incorporate the concept of “creed” as defined by the Ontario Human Rights Commission (OHRC). Creed is not defined in Ontario’s Human Rights Code, but the Commission provides some guidance based on the jurisprudence of various courts and tribunals, considering creed to include “religious beliefs and practices,” as well as “non-religious belief systems that, like religion, substantially influence a person’s identity, worldview and way of life.” The OHRC has further identified several relevant characteristics in determining “creed,” namely that it:

- Is sincerely, freely and deeply held
- Is integrally linked to a person’s identity, self-definition and fulfilment
- Is a particular and comprehensive, overarching system of belief that governs one’s conduct and practices
- Addresses ultimate questions of human existence, including ideas about life, purpose, death, and the existence or non-existence of a Creator and/or a higher or different order of existence
- Has some “nexus” or connection to an organization or community that professes a shared system of belief.

(For an extended legal analysis of Ontario’s Human Rights Code, see Part IV.B.)
This more expansive definition of “faith” with “creed” offers the benefit of including Aboriginal and Indigenous belief systems which may not comfortably fit within narrower definitions of “faith,” as well as other belief systems, and even the lack of a system of belief.

C. Spirituality

Spirituality can be a more complex term to define than faith / religion as it goes beyond established organizations or recognized communities of belief. Contemporary definitions tend to treat spirituality as more personal and something people define for themselves “largely free of the rules, regulations, and responsibilities associated with religion.” Spirituality was not historically distinguished from religiousness until the rise of secularism in the 20th century. As attitudes toward organized religion change, a growing number of people categorize themselves as spiritual but not necessarily religious or connected to an organized religion. For this group, spirituality has been individualized and secularized, and is “entirely different from its original meaning.”

D. Culture

Culture is understood differently in various academic disciplines. It is a fluid and nebulous concept which can overlap with and include notions of religion, spirituality, and creed. In pluralistic societies like Canada, many cultures can co-exist. Cultures across the globe have different practices regarding the last stages of life, and this can play an important role in providing appropriate care. When dealing with peoples’ practices and preferences, the following definition of culture may be useful:

A way of life common to a group of people, including a collection of beliefs and attitudes, shared understandings, and patterns of behavior that allow those people to live together in relative harmony, but that set them apart from other peoples. [...] These practices also produce behavior that falls within a range of variation the members consider proper and acceptable.

Although this definition is not comprehensive, it helps illustrate how beliefs, attitudes, and behaviour may be used in care decisions.

E. Culturally-Competent Health care

Culturally-competent health care has a broad range of definitions. According to the Registered Nurses Association of Ontario, cultural competence “ranges on a continuum from eliminating the negative end of destructiveness (racism and abuse) to a positive end, where cultural diversity is valued and has the potential to create innovative, transformative opportunities that maximize health, economic and social benefits.” More specifically, this may involve an understanding of the different ways a culture can influence patient behaviour in a clinical setting, so that proper communication can take place and excellent clinical outcomes are achieved. Cultural competence requires a commitment from health care providers to “understand and be responsive to the different attitudes, values, verbal cues, and body
language that people look for in a doctor’s office by virtue of their heritage”. This does not mean that health care providers must speak the same language as their patients or share the same cultural heritage. Rather, culturally-competent care requires that the “underlying values of inclusivity, respect, valuing differences, equity and commitment” should govern all interactions, policies, and practices in a health care setting. As these values are also Canadian values, in essence, culturally-competent care is a unifying model.

F. Ethnicity

“Ethnicity” is another flexible term often used to describe a nexus of traits intersecting around race, culture, and nationality. The OHRC considers the term to refer to shared cultural history or nationality, and notes that it often overlaps with “ethnic origin,” a prohibited ground of discrimination in the Code. The Code considers “ethnic origin” to encompass a wide range of characteristics, including ancestry, and that one ethnic group might be distinguished on the basis of cultural traits such as language or shared customs around family, food, dance, and music.

G. Race and Racialization

Race is a social, not a scientific, construct. The phenomenon of racism persists on the basis of misguided beliefs that perceive physical characteristics as determining a person’s views, activities, and worth, and which are used as a basis for discrimination. The most obvious physical characteristic is skin colour. However, the OHRC has also identified a number of related areas that may contribute to the racialization of a person or group of people: language, accent or manner of speech, name, clothing and grooming, diet, beliefs and practices, leisure preferences, places of origin, and citizenship.

The social process racialization is defined as the “process by which societies construct races as real, different, and unequal in ways that matter to economic, political and social life.” The OHRC outlines how, in addition to physical characteristics such as skin colour that may distinguish a person with respect to their race, other characteristics are also “racialized.” These include:

- language
- accent or manner of speech
- name
- clothing and grooming
- diet
- beliefs and practices
- leisure preferences
- places of origin
- citizenship

All of these grounds are to be considered when a human rights complaint with regards to racial discrimination is made.
Where race is referred to in this paper, it is either in the context of informant interviews or in the context of how certain sections of Ontario’s population may be racialized by health practitioners and other Ontarians.

H. Indigenous Peoples and Spirituality

Indigenous peoples in Ontario include a wide range of diverse groups that make any generalizations about “Indigenous Spirituality” a challenge.

The United Nations Declaration on the Rights of Indigenous Peoples does not define “Indigenous” but states that “Indigenous peoples have the right to determine their own identity or membership in accordance with their customs and traditions.” The OHRC defines “Indigenous” as including status, non-status, Indian, Aboriginal, Native, First Nation, Métis and Inuit.

Recognizing this diversity of practices, the OHRC declines to define "Indigenous Spirituality" due to its “diversity and Indigenous peoples’ right to define and determine this for themselves.” Nevertheless, while the OHRC observes that Indigenous Spirituality “can vary significantly among different First Nation, Métis and Inuit groups and individuals, and across different regions,” there are some commonalities. Generally speaking, Indigenous Spirituality is understood as a “way of life” (or worldview) centered on a relationship with the Creator, the land and “other beings and forms of life.”

Importantly, there is a statutory basis to recognizing Indigenous Spirituality. In May 2016, the Government of Canada formally adopted the UN Declaration on the Rights of Indigenous Peoples. Additionally, Ontario’s Human Rights Code creates a duty to accommodate indigenous beliefs and practices. (See also the discussion below in Part IV.A – B).

When discussing “Indigenous Spirituality,” this paper will refer to the spiritual beliefs and practices that Indigenous peoples identify as being “traditional” or “customary,” including more recently developed practices and syncretic innovations. This is not meant to exclude any aspect of Indigenous Spirituality that Indigenous individuals choose to adopt.

I. Informed Consent and Substitute Decision-Making

Medical decision-making in the last stages of life can raise challenges for patients, their caregivers, and substitute decision-makers (and family members) alike. Several pieces of legislation define this consent and capacity regime in Ontario.

The Health care Consent Act (HCCA) is the leading legislation. It sets out explicit requirements for obtaining consent and a tribunal-based adjudicative mechanism where disagreements arise. Under the HCCA, a health practitioner may not commence treatment unless the patient or their substitute decision-maker (SDM) has provided informed consent. This consent may be given
orally, in writing or “may be express or implied” depending on the clinical circumstances. The elements of valid consent are:

1. The consent must relate to the treatment.
2. The consent must be informed.
3. The consent must be given voluntarily.
4. The consent must not be obtained through misrepresentation or fraud.

The HCCA codifies the common law test that informed consent requires disclosure of matters that a reasonable person would require in order to make a decision on treatment. It further specifies these “matters” as including:

2. The expected benefits of the treatment.
3. The material risks of the treatment.
4. The material side effects of the treatment.
5. Alternative courses of action.
6. The likely consequences of not having the treatment.

Capacity with respect to treatment is present if the person is able to understand the information that is relevant to making a decision about the treatment, and is able to appreciate the reasonably foreseeable consequences of a decision or lack of decision. This does not apply if the health practitioner is of the opinion that there is an emergency, defined as a patient experiencing severe suffering or is at risk, if the treatment is not administered promptly, of sustaining serious bodily harm.

Other legislation provides a complimentary framework for determining the capacity and requirement to consent to personal assistive services and admission to long-term care in Ontario. Under the Ontario Long-Term Care Homes Act, 2007 (LTCHA), a long-term care resident has the “right to have his or her participation in decision-making respected.” Personal assistive services fall under the purview of the patient’s “right to be properly sheltered, fed, clothed, groomed and cared for in a manner consistent with his or her needs.” Having said this, a long-term care patient may refuse treatment or care as he or she has the right to “participate fully in the development, implementation, review and revision of his or her plan of care,” and also to “give or refuse consent to any treatment, care or services for which his or her consent is required by law and to be informed of the consequences of giving or refusing consent.”

A clinician’s determination of incapacity to consent to treatment can be challenged by the patient by appealing to the Consent and Capacity Board (CCB), an adjudicative tribunal created to rule on such disagreements. CCB panelists may include health care practitioners, lawyers, and members of the general public. The CCB may confirm the health practitioner’s finding or may determine that the person is capable with respect to the treatment, and in doing so may substitute its opinion for that of the health practitioner.
Conflicts may arise when SDMs make decisions on an incapable person’s behalf. If a SDM wishes to refuse consent to treatment, he or she must do so in a way that is consistent with prior capable wishes expressed while the patient was capable. If the SDM is unaware of any such wishes from the person, then he or she must consider the incapable person’s best interests. These considerations must take into account:

- the values and beliefs that the incapable person held when capable and that the SDM believes he or she would still act on if capable;
- whether the treatment is likely to improve the incapable person’s condition or well-being, prevent his or her condition or well-being from deteriorating, or reduce the extent to which, or the rate at which, his or her condition or well-being is likely to deteriorate;
- whether the incapable person’s condition or well-being is likely to improve, remain the same, or deteriorate without the treatment;
- whether the benefit the incapable person is expected to obtain from the treatment outweighs the risk of harm to him or her;
- whether a less restrictive or less intrusive treatment would be as beneficial as the treatment that is proposed.

Conflict may also arise when a SDM and a patient’s medical team disagree on a course of treatment or plan of care. In Ontario, the CCB adjudicates intractable conflicts with families. Health care providers may apply to the CCB to determine a SDM’s compliance with the rules of substitute decision-making (a so-called “Form G” application). Criteria used to adjudicate the issue are primarily the established prior wishes of the patients, and if this is unknown, then the best interests of the patient.

Under the HCCA, a physician must first formulate a “treatment plan” based on a patient’s diagnosis and then obtain “consent or refusal of consent in accordance with the [HCCA].” In cases where a patient lacks or is alleged to lack capacity, two types of disagreement can occur once a treatment plan is proposed to a SDM. In the first case, the SDM may refuse treatment. In that case, the physician may feel that this decision is not in the best interest of the patient or does not reflect their previous wishes, and appeal to the CCB. In the second case, the SDM may disagree with the treatment plan and demand an alternate plan from the responsible medical professionals.

The case of Friedberg v. Korn illustrates some of the conflicts that can occur in the setting of conflicts with families with respect to end-of-life care and traditional Jewish values. The patient was in a vegetative state and had previously granted her SDM power of attorney to remove life support if she ended up in such a state. The attending physician applied to the CCB to determine if her patient had expressed prior capable wishes about her care at the time she signed a power of attorney for personal care, which stated the following:

I hereby instruct that if there is no reasonable expectation of my recovery from physical or mental disability, I be allowed to die and not be kept alive by artificial or heroic measures. I do,
however, instruct that medication be mercifully administered to me to alleviate suffering even though this may shorten my remaining life.

The Substitute Decisions Act (SDA) allows for a power of attorney to be valid if the grantor is capable it at the time of execution, even if the grantor is incapable of personal care at the time. The patient’s children challenged the power of attorney on the basis that it did not reconcile with her religious beliefs. At the hearing, two rabbis presented conflicting perspectives on the matter. The patient’s rabbi claimed that the patient’s adherence to Orthodox Judaism meant that she followed more traditional values, which claimed that it was not up to the individual to decide if the quality of one’s life is worth living – it was only up to God. Although the rabbi testified that there was no obligation to prolong life in Orthodox Judaism, he stated there was nothing undignified about the patient’s condition. The act of removing life support in this context was equivalent to the act of murder. The rabbi even questioned the patient’s mental state for failing to adhere to Judaism while writing her power of attorney, as she was a practicing Orthodox Jew.

Notably, the patient did not consult her rabbi while preparing this power of attorney. Despite this, the CCB still found in favour of the patient’s power of attorney, which was written in clear, unequivocal language, and requested to end her life if she had to be kept alive by artificial means. The CCB decided autonomy and choice of the individual, irrespective of how these decisions might be perceived in retrospect in the context of religious beliefs, should be upheld.

On review by the Superior Court of Justice, however, the power of attorney was overturned. The Court reviewed a number of factors, including the patient’s religious values. The patient’s beliefs, which infused every aspect of her life, raised serious doubts about whether she understood the contents of the power of attorney. Combined with other extrinsic factors, such as inconsistencies in the power of attorney itself, and the patient’s language difficulties, the court found that the CCB had made an error in law.
VI. Other Key Materials from the LCO’s Consultations

The following are relevant excerpts from the LCO’s Discussion Paper on the Last Stages of Life, released in May 2017. For the full report, please see www.lco-cdo.org/laststages.
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Chapter 2.C: Affected Individuals, Communities and Institutions

The issues raised in the LCO’s project affect all Ontarians because each of us dies and is affected by the deaths of those around us. The LCO recognizes the advantages of a person-centred approach to caring for individuals moving through the last stages of life and their supporters. In addition, we accept that individuals belong to community networks that may share a sense of identity, discourse and experience that the LCO must take into account.

In addition to individuals and communities, the LCO’s project concerns those who shape and implement that law as professionals, government and delegated agencies. Our project strives to understand the difficulties they encounter in providing services and supports to persons who are directly affected.

In this section, we provide contextual background information on these interest groups.

1. Persons in the last stages of life

In the introduction to this paper, we explained the LCO’s inclusive approach to defining the experience of persons who are approaching the end of their life as a result of terminal illness, chronic disease or serious frailty. These conditions have different trajectories that vary in terms of their symptoms, predictability and response measures. They could deteriorate quickly or over an extended period of years. Moreover, they may unevenly affect different populations.

From the LCO’s perspective, the law must be able to reflect common goals regarding the care that persons who are dying receive, while remaining sufficiently flexible to capture their personal experiences. As a result, any potential measures to change the law must be informed by the full range of conditions that Ontarians experience and how those conditions interact with their livelihoods, care settings and access to adequate care.

Persons with cancer receive the most publicly funded services for palliative care in Ontario. Cancer is the leading cause of death in Canada. Almost half of Canadians will develop cancer in their lifetime and about 1 in 4 persons will die of cancer. The large majority of persons who develop cancer are over age 50 (89%). However, cancer can occur throughout the life course and it has been the leading cause of disease-related death in children under age 15. Despite progress in treating cancer, the Canadian Cancer Society predicts, “there will be an increasing number of cancers related to the growing and aging population”. It goes without saying that cancer imposes emotional, financial and other costs on individuals and their supporters, and it also “has major economic ramifications on Canadian society at large”.

Although cancer is the leading single cause of death, at least the same proportion of Canadians die from just a few other chronic conditions, and there has been considerable public acknowledgement of the need to better serve these individuals. For instance,
circulatory and respiratory diseases (e.g., heart disease, stroke, and chronic obstructive pulmonary disease) together are the cause of approximately 29.8% of deaths in Canada (see Figure 1).  

There are also illnesses that are admittedly less prevalent, but that also deeply affect a significant number of Ontarians who are deserving of equal treatment under the law. By way of example, there are an estimated 27,000 Ontarians living with HIV and 1000 new diagnoses each year. HIV disproportionately affects men who have sex with men, African and Caribbean Ontarians, persons who use injection drugs, Indigenous peoples as well as women among or interacting with those groups. Some of these individuals “struggle with low incomes, unemployment, depression, substance use, cognitive impairments, and stigma”. Long-term planning remains a concern. The onset on HIV-associated neurocognitive disorders (HAND) is younger than those with Alzheimer’s disease. The prevalence of milder forms of HAND is high at 50-60%, and 2-3% for more severe forms. Prevalence also does not necessarily equate to awareness; the disorder comes as a surprise for many and can trigger concerns for financial planning, the availability of HIV-designated services, or other ways of addressing vulnerabilities arising from intersecting stigma related to dementia, HIV diagnosis, and LGBTQ status.

Multiple sclerosis, amyotrophic lateral sclerosis (ALS), kidney disease and Alzheimer’s disease are further examples of progressive illnesses that could develop slowly and affect fewer people, but do eventually result in death and do merit access to high quality, personalized care. Alzheimer’s disease is the particular focus of many community organizations as its incidence is rising with Ontario’s shifting demographics toward a higher proportion of older adults. Among deaths due to chronic conditions in Canada, Alzheimer’s underwent the largest growth from 2000 to 2009 (25.4%).

Figure 1: Proportion of deaths by cause, Canada 2011
Alzheimer’s disease is the most common form of dementia. It poses special challenges along the illness trajectory because it is a “progressive and largely irreversible syndrome that is characterized by a loss of cognitive function severe enough to affect social or occupational functioning”. Thoughtful and legitimate advance care planning has thus been identified in our project as an important area of the law for this community of Ontarians.

About 90% of persons diagnosed with dementia transition from living in the community to long-term care before their death. The relationship between dementia and long-term care demonstrates the firm connection between medical condition and the location where individuals find themselves placed within Ontario’s system. Moreover, the LCO learned that certain care settings are more or less equipped to provide dedicated care for persons who are dying, leading to disparities in access based on medical condition.

Yet individuals’ experiences with death and dying are influenced not only by their medical condition, but also factors including their access to information, place of residence and informal supports, which may determine whether they can or cannot access suitable treatments and accompaniments. Therefore, as much as possible, in this paper we try to highlight connections between social factors, access to care and the role of legal frameworks.

We hope to learn more about these connections in our consultations.

2. Caregivers and other family and friends

Whether the law hinders or nurtures caregivers greatly affects their ability to support persons who are dying and, also, the caregivers’ own wellbeing.

At some point in life, most Ontarians act as a caregiver to a family member or friend. Up to 75% of care in Canada is provided voluntarily by unpaid individuals and 97% of patients receiving home care in Ontario get assistance from a caregiver. With Ontario’s aging population and a “continuing shift away from institutional, hospital-based forms of care toward more home and community-based care”, caregivers occupy an integral role in the health system that is becoming still more vital.

Age-related needs are the single most common problem requiring help in Canada, but an equal proportion of persons receive assistance to manage chronic diseases, and over one quarter (28%) of caregivers have supported a person through terminal illness. In Ontario, specifically, Health Quality Ontario (HQO) estimates that recently 35,000 persons a year acted as end-of-life caregivers in a private home or long-term care facility.
At the end of life, as an individual’s condition deteriorates, there is an “increasing need for assistance with daily tasks”. 140 As such, persons at the end of life and their caregivers struggle with the implications of advanced medical conditions, which include symptoms as well as practical demands. Caregivers lend their support through a great variety of activities that include emotional comfort, grocery shopping, cleaning, providing transportation, coordinating appointments, managing medications and helping with hygiene. 141

Caregivers told the LCO that the time and effort required by such daily tasks can be incredibly difficult to manage without supports (such as paid benefits and respite) and that Ontario’s existing law and policy framework is wanting in this respect.

Thus, there are positive aspects as well as challenges arising from caregiving in the province. Research on caregivers’ perspectives has found that most of them assume the role because they wish to do so. 142 Many find meaning in it and they experience feelings of reciprocity in their relationships with those whom they care for. 143 As the Change Foundation reports, “Caregiving can bring incredible joy, rewarding relationships, personal satisfaction and depth to the human experience; it can be enriching and life defining”. 144

Nevertheless, it is essential to acknowledge that caregivers often function in worrying conditions. In a report on supports for end-of-life caregivers, HQO found that

Providing informal care for people at the end of life can be burdensome, and studies have shown that it can have negative health impacts for the caregivers, such as sleep problems, fatigue, psychological distress (i.e., depression and anxiety), burnout, and an increased risk of mortality. Studies have also shown that informal caregivers tend to suffer from financial strain. Furthermore, it is important to recognize that more people are now working outside the home, which may further add to the burden of informal caregiving. 145

This discussion paper examines the adequacy of existing supports in Ontario that are intended to relieve difficulties, such as those listed above.

Additionally, we consider the needs of family and friends who may not be caregivers but who are, nonetheless, touched when someone close to them passes away. As with caregivers, family and friends are important stakeholders in the LCO’s project because they are bereaved. They may also assume responsibility over practical issues that must be dealt with after a person has died, such as obtaining a death certificate and arranging funeral services. Consequently, part of the LCO’s task is to review the current state of benefits that family and friends receive (e.g., leave from work, counselling) and related challenges.

- Detailed information on existing services and supports for caregivers, family and friends and on the challenges they face is found in chapter 5.D.1.
3. **Professionals**

There is a wide range of professionals who provide services and supports in this area including the following:

**Health care providers:** Health care providers in this context include family physicians, medical specialists, registered nurses and nurse practitioners, social workers, personal support workers, pharmacists, psychologists and psychiatrists. Health care providers work in a variety of environments, are regulated separately and may be funded under different arrangements. However, palliative care emphasizes coordinating services in interprofessional teams and capacity building among providers so that not only specialists but also primary level providers can address patients’ basic needs. Health care providers are the frontline workers who interact most closely with persons who are dying and their supporters.

**Legal professionals:** Legal professionals with an interest in this project include legal clinics, such as the Advocacy Centre for the Elderly (ACE) and ARCH Disability Law Centre, and members of the health, and trusts and estates bars. Besides legal professionals who have specialized expertise in this area, general practitioners are called upon to assist in related matters, for example, drafting powers of attorney, estates planning and legal representation in disputes.

**Ethicists:** Ethicists develop and apply analytical frameworks to resolve controversial questions that engage medical, legal, philosophical, ethical and other viewpoints. Ethicists practicing in this area work with facilities, government and delegated agencies and research institutions to conduct studies, craft policies and mediate case-based decision-making.

**Facility operators:** Facilities are hospitals, long-term care homes, residential hospices, community clinics and other institutions that oversee service delivery within their authority. For instance, some hospitals have palliative care units and palliative consult teams, and long-term care homes are statutorily required to provide end-of-life care.

**Academics, educators and trainers:** The LCO heard there is a high level of concern about the lack of education and training for professionals who regularly encounter persons in the last stages in life. Furthermore, there is a lack of information for members of the public on relevant topics, such as eligibility for services and consent to treatment. As such, it is essential to include regulatory colleges, professional associations, and academics in law and the health sciences in the LCO’s project. Beyond education and training, academics also contribute greatly to the availability of trustworthy research.
4. Government and delegated agencies

Core government and delegated agencies described below are also presented in a flowchart in section 4.B.2, Figure 2, Ontario’s Framework for Publicly Funded Care in the Last Stages of Life.

Government: Overall responsibility for health care in Ontario rests with the MOHLTC. The MOHLTC sets priorities for the sector as a whole and has a stewardship role that focuses on strategic planning, policy development, investment, system-wide performance and accountability. The MOHLTC directly plans, funds and oversees certain services while delegating the majority of funding and administration to external agencies, such as the Local Health Integration Networks (LHINs) and Cancer Care Ontario (CCO). For instance, the MOHLTC funds residential hospices and physicians and is leading the development of a strategy on palliative and end-of-life care. Apart from the MOHLTC, the issues raised in this project cut across government ministries and departments, for instance, MAG, the Ministry of Community and Social Services, Ministry of Children and Youth, Office of the Public Guardian and Trustee, Ontario Seniors’ Secretariat and Office of the Chief Coroner.

Ontario Palliative Care Network: The OPCN is a partnership of community stakeholders, such as health providers, HQO, the LHINs, CCO, health system planners, patients and their families. The OPCN is mandated to be a principle advisor to the government on hospice palliative care in Ontario. It is accountable for quality improvement initiatives, data and performance measurement and system level coordination along with supportive regional implementation of high-quality, high-value hospice palliative care in Ontario.

Local Health Integration Networks: Ontario’s 14 LHINs are Crown agencies that plan, fund and oversee the accountability of far-reaching health services in the province, including hospitals, long-term care homes and community support services. Under Bill 41, Patients First Act, 2016, which received royal assent December 8, 2016, the LHINs are proposed to assume greater responsibility for primary care, long-term care placement coordination, and home and community care (the latter two have otherwise been the responsibility of the Community Care Access Centres (CCACs)). Home care is intended for those who can live independently when they receive nursing, homemaking and personal support services. The LHINs are mandated to promote the integration of health services within their regions. In furtherance of that mandate, all LHINs have a Regional Palliative Care Network that brings stakeholders together to strengthen quality, integrated services. Planning and implementation at the local level will be through the governance structure of these 14 Regional Palliative Care Networks, which will aim to ensure a system-wide approach to palliative care that is patient focused. The networks are connected through the Provincial-End-of-Life Network, which fosters strategic guidance, collaboration and the dissemination of best practices. The LHINs are core participants in the OPCN.
**Cancer Care Ontario:** Cancer Care Ontario is mandated by the MOHLTC to improve cancer and kidney disease services, and access to care for key health services, through strategic guidance and funding arrangements with facilities and service providers. CCO creates and maintains information systems, establishes guidelines and standards, tracks system-wide performance, and delivers care at the local level through 14 regional cancer programs that correspond to the LHIN regions. CCO devotes considerable resources to improvements in palliative care, for example, by developing evidence-based standards and piloting early identification tools.\(^{152}\)

**Health Quality Ontario:** HQO is a Crown agency that collects and analyses information on the quality of health care in Ontario, in part, through the review of annual performance reports that health care organizations are required to submit (called quality improvement plans). HQO publicly disseminates its reports and advises government and health care providers on evidence to support improvements.\(^{153}\) HQO has conducted research to generate an evidentiary framework for end-of-life care.\(^{154}\) HQO is a core participant in the OPCN.

**Regulatory colleges and professional associations:** Regulatory colleges oversee health care professionals’ responsibilities by drafting practice guidelines, standards and policies, and by undertaking enforcement. Professional associations advocate on behalf of their members in consultation with the government and regulatory colleges. Ontario regulatory colleges and professional associations have released documents relating to palliative and end-of-life care, decision-making and physician-assisted dying.\(^{155}\)

**Administrative tribunals:** Three administrative tribunals adjudicate disputes relevant to care in the last stages of life. The Consent and Capacity Board (CCB) adjudicates disputes about capacity and decision-making, including issues surrounding the suitability of a substitute decision-maker’s (SDM) provision of consent for end-of-life treatments. The Health Professions Appeal and Review Board (HPARB) considers the reasonableness of regulatory college complaints committees’ findings about matters of professional conduct, for example, whether a health care provider has met practice standards in delivering palliative care. Finally, the Health Services Appeal and Review Board (HSARB) adjudicates complaints about eligibility for home and community services that have been dismissed by prior designed complaints committees.

**Office of the Patient Ombudsman:** The Patient Ombudsman is a recent addition to Ontario’s health care system with the first appointment to the role in December 2015.\(^{156}\) The Patient Ombudsman’s responsibilities include responding to unresolved complaints from patients and caregivers about the patient’s health care experience at a health sector organization, which includes hospitals, long-term care homes and centres for coordinating home care.\(^{157}\) Because the operationalization of the office is relatively new, there is little information currently available to understand its role and effectiveness. The Patient Ombudsman’s mandate does, however, include responding to complaints from patients and caregivers, investigating a health sector organization in response to the complaint or on her own initiative, making recommendations to a health sector organization, making reports to
the MOHLTC and annual recommendations, and providing reports to LHINs as appropriate.  

5. **Community organizations**

Some community organizations overlap and collaborate with professionals working in this area of the law. Nonetheless, they have separate interests as communities advocating for the rights of their constituencies.

**Advocacy organizations:** Community organizations with an interest in this project include those advocating for patients, older adults, persons with disabilities and caregivers. Often advocacy organizations have conducted research, carried out law reform endeavors and published materials for public education. Hospice Palliative Care Ontario (HPCO) is a prominent voice for advocacy in this area. HPCO is also the Secretariat for the Quality Hospice Palliative Care Coalition of Ontario whose membership includes provincial associations and organizations, such as universities, community organizations and professional associations, among others.

**Faith and cultural communities:** Religion and culture strongly influence beliefs and practices surrounding death for individuals, families, health care providers and communities. Faith and cultural leaders have begun to address ethical approaches to the last stages of life in recent years with some having delivered positions on the appropriateness of different courses of treatment. They may also be involved in supporting persons as they move through the dying process by providing counsel, leading prayer, mediating disputes and performing rituals after death.
Chapter 3.C: Palliative Care

1. What is palliative care?

The term “palliative care” describes both a philosophy of care and a wide-range of services that are provided to realize the philosophy for individuals and society at large.

Referring to palliative care as a “philosophy” captures its nature as a general approach to providing care that is rooted in assumptions, values and principles.

For example, the World Health Organization describes palliative care as “an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness…”, among other characteristics. In Ontario, the MOHLTC, LHINs and Quality Hospice Palliative Care Coalition of Ontario define palliative care as,

[A] philosophy of care that aims to relieve suffering and improve the quality of living and dying. It aims to help individuals and families to:

- address physical, psychological, social, spiritual and practical issues, and their associated expectations, needs, hopes and fears
- prepare for and manage self-determined end-of-life choices and the dying process
- cope with loss and grief during illness and bereavement
- treat all active issues and prevent new issues from occurring
- promote opportunities for meaningful and valuable experiences, personal and spiritual growth, and self-actualization.

Individuals with palliative care needs are those where much (but not necessarily all) of the focus of care is the relief and prevention of suffering and improving quality of life and comfort.

This philosophy is also translated into practice. The “service” dimension of palliative care refers to the actual medical, social and legal services and supports that individuals receive on day-to-day basis, such as treatment, facilitating health care consent and advance care planning conversations, social activities and counselling. These services may be offered by a number of providers alone or in teams across the different care settings mentioned above, which include

- private homes
- long-term care homes
- retirement homes
- hospitals
- residential hospices
• day programs.

A person’s actual care setting, services and supports will depend on her unique needs but, ideally, the approach to caring for each individual will be consistent with the goals that palliative care seeks to achieve.

2. Origins and evolution of palliative care

i. Early years of advocacy and government involvement

In Ontario, the provision of palliative care as a publicly funded service has resulted from the advocacy efforts of committed health care providers and grassroots organizations. Since the 1960s, palliative care has progressively gained increased attention, publicly and within government, and it has become an integral part of the health care system.

The 1970s and 1980s were “foundational years” for the palliative care movement in Ontario. Ontario’s first community-based hospice opened in 1979, an institute for research and education was founded in 1983 and, by the late 1980s, there were two provincial hospice palliative care organizations (which eventually merged into Hospice Palliative Care Ontario). Important centres of excellence emerged in and around that time, such as the Temmy Latner Centre for Palliative Care, as did notable programs providing home-based palliative care.

Whereas during its early years of development palliative care was aimed at persons with terminal illness, especially cancer, it gradually became more inclusive of different conditions along the life-course. Throughout this early period, however, palliative care services reflected the demands of local challenges – they were largely confined to isolated programs established by community advocates in the locations where they worked.

Federal and provincial government involvement in palliative care grew from the 1990s on. Ontario’s commitment of funding in 1992 for community palliative care was a milestone for the movement, even if it was “not closely coordinated or distributed across the province”. Furthermore, the federal Senate brought palliative care to the national stage in the 1990s, when it began a series of report on the subject.

In 2005, Ontario launched a three-year End-of-Life Care Strategy, which aimed to shift end-of-life care from acute settings to the home and to enhance the coordination of service delivery. Important components of the strategy were its funding for community providers and the establishment of palliative care “networks” embedded within some of Ontario’s LHINs. Not all LHINs have established networks and they do not all operate with the same degree of representation and participation. The networks that are functional bring together individuals and organizations interested in palliative care in order to promote integrated care, and they are linked at the provincial level.
An evaluative review of the *End-of-Life Care Strategy* found that it had some positive impacts, but also challenges. For instance, more patients had been served and the strategy may have resulted in broader identification criteria; however, “individual patients did not use more home care or less acute care services after the implementation”. And beyond the creation of the networked-approach to management at the LHIN level, the strategy did not establish an overarching regulatory framework for palliative care.

ii. **Agreement on a Declaration of Partnership**

In 2011, acknowledging that there was still “a tremendous gap” in services, the MOHLTC, LHINs and Quality Hospice Palliative Care Coalition of Ontario (QHPCCO) agreed on a vision document “to provide equitable access to safe, comprehensive and high quality palliative care and support for individuals and their families across the province”. The document, *Advancing High Quality, High Value Palliative Care in Ontario: A Declaration of Partnership and Commitment Action* (Declaration of Partnership) accomplishes a number of tasks, including elaborating a coherent definition of palliative care, agreeing on core values and assumptions, and formulating a model for service delivery.

The *Declaration of Partnership* asserts that palliative care may enhance other types of restorative and rehabilitative care, is most effectively delivered in teams and should be integrated at multiple scales within Ontario’s regulatory framework – at the clinical, organizational and overall system levels.

Important to the LCO’s project, it also recognizes an inclusive approach to identifying persons who could benefit from palliative care. According to the *Declaration of Partnership*, palliative care is “appropriate for any individual and/or family living with, or at risk of developing a life-threatening illness, at any time they are prepared to accept this type of care and support”.

It links chronic disease management with palliative care, so that coordinated planning occurs throughout the chronic disease and aging process. Moreover, its model for service delivery requires that “[i]n each setting where individuals die, there is a clearly defined care program that is founded on the palliative care philosophy and approach”.

In short, the *Declaration of Partnership* is the most comprehensive, ambitious vision for palliative care in Ontario to date.

A steering committee was formed in 2012 to implement the *Declaration of Partnership*. The committee was comprised of representatives from government, LHINs, CCACs, Cancer Care Ontario, professional associations, hospitals, community organizations and others. It held a series of meetings and delegated work items to be undertaken by a Clinical Council and Working Groups, some which produced expert reports.
Despite these initial steps, however, in December 2014 the Auditor General of Ontario released the results of an investigation into the state of palliative care, which found that “three years after its creation, significant work still needs to be done to meet most of the commitments made in the Declaration of Partnership”.\textsuperscript{179}

The Auditor General observed that services in Ontario evolved in a “patchwork fashion” according to the sites in which advocates were located and that, “although efforts have been made to create an integrated, co-ordinated system... no such system yet exists”.\textsuperscript{180} Notably, she found that Ontario lacks standard eligibility criteria for services, a common process to identify patients, equitable access to palliative care across the regions and public education.

Among other recommendations, the Auditor General of Ontario proposed the design of a government-approved policy framework:

> The Declaration of Partnership should be linked to a policy framework for approval by the government. This framework could outline the necessary direction and funding to support the implementation of the commitments.\textsuperscript{181}

### iii. Proposal for a provincial strategy and the Ontario Palliative Care Network

In November 2014, while the Auditor General’s report was being prepared, the Minister of Health and Long-Term Care mandated his Parliamentary Assistant, John Fraser, to lead the development of a strategy on palliative care. In addition, Fraser was mandated to oversee the expansion of residential hospices to almost double the number of beds in the province.\textsuperscript{182} Fraser held 16 roundtables with dozens of individuals, organizations and hospices over the course of several months.\textsuperscript{183} The results of his consultations were then reported in the \textit{Palliative and End-of-Life Care Provincial Roundtable Report} (Fraser Report).\textsuperscript{184}

The \textit{Fraser Report} was released in March 2016 along with an announcement that the government invested increased funding through the Provincial Budget to strengthen community-based hospice and palliative care.\textsuperscript{185}

The \textit{Fraser Report} confirms much of what had been recorded previously in the \textit{Declaration of Partnership} and Auditor General report on the state of palliative care in Ontario. It also makes new findings of interest to the LCO’s project that we rely on in this discussion paper. Of particular interest to our project are the following findings:

- Families and caregivers find the health care system difficult to navigate.
- Diverse communities face unique barriers accessing palliative care, such as rural and northern communities, francophone persons, cultural groups and Indigenous peoples.
• Long-term care homes should be a part of the continuum of palliative care.\textsuperscript{186}
• Caregiver supports should be improved.
• Public education and awareness should be enhanced.

\begin{itemize}
  \item The LCO’s project examines these issues as part of the remaining chapters of this report.
\end{itemize}

In conjunction with the Fraser Report’s release, the government also announced the inauguration of a provincial-level “network” that brings together various partners to drive implementation of consistent quality hospice palliative care across the province, called the Ontario Palliative Care Network.\textsuperscript{187}

**Ontario Palliative Care Network**

The OPCN is an organized partnership of community stakeholders, health service providers and health system planners, accountable for the development of a coordinated, standardized approach to the delivery of hospice palliative care in Ontario. The OPCN’s mandate is to

• act as a principal advisor to government on hospice palliative care in Ontario
• be accountable for quality improvement initiatives, data and performance measurement and system level coordination
• support regional implementation.

The OPCN governance structure is multifaceted. It includes an Executive Oversight with representation from the LHINs, Quality Hospice Palliative Care Coalition of Ontario, Cancer Care Ontario and HQO. There are several Advisory Councils that focus on clinical improvements, data and information, implementation and community partnerships (with representation from diverse providers, care settings, geographies and patient groups). There is also a Secretariat with staff to support the OPCN operational and tactical activities and, generally, execute the OPCN mandate.

As part of the OPCN structure, Regional Palliative Care Networks are being created for each of Ontario’s 14 regions. For each region, the LHIN CEO and regional cancer program VP will jointly oversee the networks to ensure that planning and implementation is aligned with the OPCN’s provincial standards.

The OPCN builds on existing institutional arrangements in Ontario. Therefore, providers will continue to deliver palliative care through the LHINs, MOHLTC and CCO. However, they will do so in conformity with the new provincial standards.
iv. **Ongoing non-governmental initiatives**

Another way in which the government has recently committed to improve palliative care is through partnering with HPCO to provide training to hospice volunteers.\(^{188}\) Beyond this initiative and others that the government supports, community organizations, regulatory colleges and professional associations have maintained their record of leadership in this area, and they develop independent programs and resources.

For example, the Registered Nurses’ Association of Ontario and CPSO have drafted policies and practice guidelines for providers.\(^{189}\) The Ontario Medical Association (OMA) has been leading an end-of-life strategy and has published guiding documents.\(^{190}\) HPCO offers a great variety of training and educational opportunities on all aspects of palliative care and it has initiated a community of practice on health care consent and advance care planning.\(^{191}\)

Given the importance of non-governmental initiatives in this area, we have listed associated publications alongside key government documents in Figure 4, below.
3. Emerging directions: the public health approach to palliative care

i. Introduction

The public health approach to palliative care is a theoretical model that complements the main tenets of palliative care. It aims to have palliative care treated as a matter of broad public interest.

During the LCOs consultations we were urged to consider reviewing the public health approach as the next step in an evolving philosophy of palliative care. However, in our review process, it became apparent that the approach itself is still developing and, therefore, difficult to study. Indeed, scholars acknowledge the “breadth”, “ambiguity” and “lack of clarity” in this emerging area\textsuperscript{192} – there are limits to the available information among proponents, researchers and also for the LCO.

In this section, we nonetheless seek to draw out some of its major features from the existing literature. We pose questions that we believe require further clarity throughout and, particularly, in the concluding part. Notably, we ask what the public health approach might look like on the ground as a matter of law reform.
ii. **Overview of the public health approach**

Not unlike palliative care, generally, the public health approach is premised on the “recognition of the limitations of traditional models of health care delivery”. Some of the principles shared between palliative care strategies and this approach include person- and family-centred care, involvement of non-specialists (such as primary care providers, social workers and PSWs), and equitable access for the entire population.

However, the public health approach has a distinctive focus on social aspects of care: it seeks to integrate palliative care into everyday living through raising public awareness, supporting healthy attitudes about death and dying, and fostering community engagement. It critiques palliative care focused on “inpatient, outpatient, day care and home care services and not community development”.

The public health approach overlaps with initiatives that go by the terms, “compassionate communities”, “compassionate cities”, and “health promoting palliative care”. These initiatives have progressed over several decades in parallel with the palliative care movement and they have been integrated into government strategies in various jurisdictions.

The major focus of these initiatives that can be discerned from the literature (and that do not overlap with recent palliative care models), include

- community capacity-building and engagement
- public awareness and education about death and dying.

We discuss these two major features of the public health approach below.

iii. **Community capacity-building and engagement**

As discussed previously in this paper, advancements in palliative care first arose at the community level with the development of hospices and other centres of excellence. The public health approach to palliative care seeks to build on this history of past successes at the local level and to foster more community engagement with government support.

The rationale for community engagement is based on a number of principles. First, given the social-orientation of this approach, it views the responsibility to care for persons who are dying and their supporters not only as a responsibility for government, but also for surrounding community, including neighbours, workplaces, schools, local businesses and others.

It is important to remark that the concept of community responsibility should not be mistaken for offloading responsibility onto communities in order to decrease government input and achieve certain outcomes. Rather, community engagement from the public
health perspective can be understood “as an empowerment model” that strengthens community capacity to develop responses to caring for their own members. 200

Prof. Allan Kellehear, the founder of health promoting palliative care, explains that some of the problems persons living with life-limiting illness encounter include social isolation, family breakdown, premature job loss and financial strain. 201 Many of these problems, he says, “are not easily addressed by health services”. 202 Moreover, he claims that palliative care services have struggled to provide bereavement support to family and friends. 203

Whereas families have long shared responsibility with the health care system to provide for persons in the last stages of life, advocates of the public health approach claim that community members also have a role to play in addressing such challenges. In Kellehear’s words, “Health is everyone’s responsibility”. 204

According Kellehear and other advocates, the public health approach means enabling communities to provide the social aspects of palliative care (e.g., food, transportation, company) that supplement clinical interventions provided through the health care system. Community engagement they claim,

allows for the provision of a continuous background level of support that is developed pertinent to specific needs within the community, upon which discrete episodes of professional intervention can occur. 205
Examples of Community Capacity-Building and Engagement

There are many examples of community capacity-building and engagement for palliative care in Ontario and abroad. In Ontario, local initiatives that emerged organically alongside the palliative care movement have begun to expand and self-identify with “compassionate communities” through initiatives, such as Pallium Canada’s national and the HPCO’s provincial compassionate communities community of practice.206

The Windsor-Essex project is an initiative that gives a good example. Among other components, it involves mobilizing youth, faith, cultural, senior and informal social networks to generate volunteer opportunities; introduces a phone service for advice in distressing situations; and includes the formation of care networks for people in the last year of life with dementia or who need personal support with daily living activities. The Windsor-Essex project involves partnering with government agencies and departments at the federal, provincial, LHIN, county and municipal scales.207

Compassionate communities have also received considerable attention and support in other common law jurisdictions, including England, Australia and Scotland. In Australia, for instance, a national palliative care association published a guide for local health care service providers to foster community development and education.208 A number of local initiatives have also been funded through the federal Department of Health and Ageing “Caring Communities” program.209

A “Compassionate Cities Charter” is being used by local governments to assist them formulate and achieve related goals.210 The charter signals a government’s commitment to ensure that institutions within their jurisdiction support wellbeing in the context of death and dying, including schools, workplaces, faith communities, correctional facilities and shelters.211 In Ontario, the Windsor-Essex project has created its own charter and statement of values.212

A notable claim of the focus on community engagement is that it is particularly supportive of marginalized and disadvantaged groups.213 For instance, the public health approach has been tendered as a framework for “age-friendly communities” that promote participation and autonomy for older persons nearing end-of-life.214 Community-mobilization has also been used to empower First Nations health care providers to create culturally appropriate locally designed and controlled palliative care programs in four diverse First Nations communities in Ontario.215

Given the public health approach’s focus on community capacity-building and engagement, the LCO would like to know more about how legal frameworks might empower community members to become involved in palliative care in a manner that is voluntary and not motivated by resource concerns.
iv. Public awareness and education

Public awareness and education is another core feature of the public health approach to palliative care.

In Ontario, public awareness of palliative care is limited. However, a lack of knowledge or misperceptions can inhibit access to services and supports. The Auditor General’s report recognized this connection between education, awareness and access to care. It explains,

To help patients who could benefit from palliative care, more people need to learn what palliative care entails, what services exist in the community, and how to access these services. Otherwise, there is a risk that patients will suffer unnecessarily by not receiving timely palliative care.  

Participants in the Fraser Report consultations also spoke about the public’s misperceptions about palliative care, which they view as a final option when “nothing else is working”. The report explains: “Too many people think that palliative care just helps people die comfortably, instead of helping them to live longer and better”.

The public health approach recognizes the need for better understandings of palliative care, but it also focuses more specifically on the need for transformational change in the public’s perceptions of death, dying, loss and bereavement.

A core objective of the approach is to promote healthy, life-affirming attitudes about dying and grieving as normal human experiences. Thus, it seeks to combat “death-denying” practices that, potentially, lead to “many people and their loved-ones being unwilling or unable to openly discuss their preferences and priorities for care and death, views on organ donation, prepare a will or plan a funeral”.

During the LCO’s consultations, we heard from numerous stakeholders who held views akin to this perspective. For example, we heard that more needs to be done to secure the dignity of patients and their supporters by helping them understand the repercussions of their situation and the available options. This could better enable them to be actively engaged as participants in their own life course. We also heard that key messages from the public health perspective for Ontario would be a shift in thinking about death, dying, loss and bereavement.

Community engagement is one of multiple channels through which the public health approach aims to enhance awareness. Other channels might include combatting negative attitudes from an early age in school curriculums; sensitizing non-specialized health care providers to identify those who might benefit from palliative care (such as family doctors and primary care nurse practitioners); and encouraging open conversations with individuals, families and providers about health care consent and advance care planning.
v. Incorporating the public health approach into legal frameworks

Earlier in this chapter, we summarized Ontario’s regulatory framework for health care planning and delivery. The question for the LCO’s project here is how the public health approach to palliative care would feature in this regulatory framework, if it were determined to be beneficial for Ontarians. This central question raises several lines of inquiry.

For instance, it is unclear to the LCO whether proponents of this approach seek to *replace* palliative care models with something wholly different or to *complement* dominant models with improved government support for community engagement and public education. In either case, we would like to know more about what these proposals would require in practice in terms of laws, policies, funding and service delivery.

Presently the MOHLTC and LHINs have ongoing initiatives both on community engagement and public education. For instance, local palliative care initiatives may already be aligned with the compassionate communities model, such as residential hospices and community support services (e.g., visiting hospice volunteers, day programs, and pain and symptom management education). These initiatives can be viewed as a marriage of bottom-up organizing by community members and top-down support from the government.

Furthermore, the Fraser Report highlights stakeholder submissions on the desire for innovative community-based models, and enhanced public awareness and education. And the Erie St. Clair LHIN has explicitly recognized the public health approach as well as community capacity-building and public awareness in its regional palliative care strategic plan.

Taking into account these existing initiatives, we ask whether increased government support for such efforts would fulfil aspirations for the public health approach.

The LCO is also aware that advocates in this area are seeking to link palliative care directly to public health systems.

In England and Scotland, partnerships between palliative care and the public health system have been called for in government policies on palliative care. Additionally, in Scotland, the national Public Health Network has issued a report with recommendations for the public health system to develop the roles of public health specialists in the context of palliative care.

At this moment in the project, the LCO has been unable to determine how successful these efforts are on the ground. Furthermore, we wonder how applicable these comparisons might be in the context of Ontario’s unique public health system.

Previously in this paper we stated that the MOHLTC plays a role in funding and overseeing public health in Ontario. According to the MOHLTC, “The primary focus of public health is
the health and well-being of the whole population through the promotion and protection of health and the prevention of illness". Public health programs and services seek to address determinants of health – such as income, social support networks, education, working conditions and personal coping skills – and to reduce health inequities.

A fundamental concern of the public health system is health promotion and chronic disease prevention through public awareness and capacity-building for municipalities, schools, workplaces and other community partners – all of which might provide relevant experience for similar initiatives addressing palliative care.

However, a substantial part of public health work in Ontario is concerned with issues that are quite distant from palliative care principles and practices, such as emergency preparedness, environmental safety standards and infectious disease prevention and control.

Moreover, public health institutions are quite separate from the overall health care system. Under the Health Protection and Promotion Act, programs and services are managed by 36 local boards of health and delivered by public health units with specially qualified staff. Also, municipalities are significant partners in funding and administering the public health system.

Given the unique design of Ontario’s public health system and its mandate, further information is needed to understand what advocates propose. The LCO would like to know more about what proponents believe involving Ontario’s public health system in the planning and delivery of palliative care would achieve and require.

4. Issues for the LCO’s project

The above discussion makes it clear that Ontario’s regulatory framework for palliative care is in a state of change. Reliable sources report that Ontario’s system for palliative care suffers from a lack of coordination and difficulties serving certain populations – all of which have led to inequities in accessing care. The MOHLTC is moving forward to address these challenges with new investments and the establishment of a provincial network to coordinate and improve palliative care across the province, the OPCN.

As mentioned previously, the LCO’s project avoids reviewing issues that fall within the MOHLTC and the OPCN’s priorities. The most notable issue areas that we do not address as a result of their mandates are

- institutional coordination
- education and training for health care providers
- the overall enhancement of Ontario’s palliative care services and supports.
The LCO’s project does, however, address issues in Ontario’s developing regulatory framework that supplement the MOHLTC and the OPCN’s efforts.

Accordingly, among other issues, the LCO’s project seeks to address the concerns of communities with unmet needs to ensure equitable access to care regardless of characteristics such as their age, sexual orientation and identity, abilities, and place of residence (chapter 5). We review benefits for caregivers and other family and friends (chapter 5.D.1). And we also review navigational supports that could assist individuals as they transition through the system from one care setting to another (chapter 7).

In addition, in this chapter, we presented various options for the integration of public health approaches into Ontario’s legal frameworks. A question relating to this issue is posed at the end of this chapter at section 1, “Questions for Discussion”.
Chapter 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”.

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.

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.

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.

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.

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”.

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.

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<thead>
<tr>
<th>Figure 5: Ontario’s Communities with Unmet Needs</th>
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<tr>
<td>• Caregivers, and other family and friends</td>
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<td>• Older adults with serious frailties</td>
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<td>• Persons living in long-term care</td>
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<td>• Persons living in retirement homes</td>
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<td>• Francophone persons</td>
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<td>• Person for whom English is not a principal language</td>
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<td>• Persons with disabilities</td>
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<td>• Children and infants</td>
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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”. 242

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. 243

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”. 244 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. 245
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...”

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. 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. In Carter, the Supreme Court affirmed that concerns about autonomy and quality of life can be treated as liberty and security rights.
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)\(^{250}\)
- 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)\(^{251}\)
- 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. 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.

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. Studies show many caregivers perceive their role in a positive light, as a reciprocal process that benefits them and the persons they support. However, there is also reliable evidence demonstrating that negative health, social and financial repercussions of caregiving are common.

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. Many caregivers report feelings of worry, anxiety, fatigue, depression, loneliness and being overwhelmed. Almost 1 in 10 caregivers also report financial hardship resulting from their responsibilities including borrowing money, using savings and selling their assets.
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.

The *Employment Standards Act, 2000* protects employees from losing their job when they take leaves of absence to care for family members, persons “like a family member” or in emergencies.\(^{258}\) The provisions governing leave are quite complex because there are several types and each may depend on factors, including relationship, prognosis and length of employment.

Leave is also limited by a maximum number of weeks within a period of time. For example, under one type of leave called “Family Medical Leave”, employees are entitled to take up to 8 weeks to care for an individual who has a significant risk of death within a period of 26 weeks. If the person does not pass away within that 26 week period, employees are entitled to another leave of up to 8 weeks, but only in a subsequent 26 week period.\(^{259}\)

A consequence of existing requirements is that caregivers may exhaust their entitlements or may not be able to take leave without interruptions. Interruptions can be especially pronounced where the underlying condition causes ups and downs over a lengthy period of time. Continuity in leave for the actual time it takes to care for persons who are ill can therefore be difficult.\(^{260}\) Furthermore, while Ontario’s protections were recently expanded,\(^{261}\) they do not match protections for federally regulated employees. Under the *Canada Labour Code*, a type of protection similar to Family Medical Leave entitles employees to an additional 20 weeks.\(^{262}\)

For employees who are able to take leave, the *Employment Standards Act, 2000* does not guarantee pay. Ontarians may be eligible for federal EI benefits, including the “Compassionate Care Benefit”.\(^{263}\) Since EI is aligned with federal leave entitlements, these benefits may be available for 26 weeks.\(^{264}\) That said, the LCO has heard that because they are linked to job-status, caregivers may not be eligible if, for instance, they have not accumulated sufficient work hours, are self-employed or are precarious employed. Furthermore, benefits are only available to caregivers of persons with a significant risk of death or critically ill children – they neglect to include other chronic conditions.\(^{265}\)

Short-term respite provided through the health system and income tax credits are other sources of caregiver support.\(^{266}\) On the whole, however, stakeholders told the LCO that existing caregiver benefits in Ontario are inadequate. The Fraser Report documents similar sentiments with respect to current levels of home care (which could offset the need for caregiving), respite services and financial compensation.\(^{267}\)
The LCO is aware that community organizations in Ontario are advocating for a caregiver allowance, separate from employment regimes. In Canada, Nova Scotia provides such a benefit in the amount of $400 per month. The UK and Australia also provide a spectrum of financial allowances for caregivers as well as statutory protections for “flexible” working arrangements.

In addition, the UK and Australia have legislation that specifically defines “carer”, and centralized gateways for informational supports (i.e., online portals and call-centres). One of the challenges for caregivers identified in the LCO’s consultations is Ontario’s lack of such formal recognition of caregivers as a unique beneficiary group, which could improve the coordination of dedicated services and supports.

**Grief and bereavement services**

Aside from direct supports for caregiving activities, persons who are caregivers, and other family and friends, have expressed the need for improved grief and bereavement services.

The Declaration of Partnership accepts that grief and bereavement care are a core part of the vision for palliative care in Ontario. Access to grief and bereavement supports are listed among the document’s priorities for action and it calls upon the LHINs and regional palliative care networks to ensure that appropriate support is available before and after a person dies.

Generally speaking, in Ontario counselling and psychological care are not covered by public health insurance, unless they are provided by psychiatrists (because they are medical doctors) or offered through government-funded hospitals, clinics and programs. There are many passionate and committed organizations that coordinate volunteering programs to help family and friends work through their experiences, and these often receive some public funding.

However, stakeholders informed the LCO that communities require better capacity to provide the supports they strive to offer. As it is now, services are fragmented and psychological support has not been adequately integrated into palliative care. We were informed that, as a result, Ontario effectively has a “two-tiered” system for therapy, divided between those who can pay for private services and those who cannot.

We also heard the ESA provides insufficient leave to face the challenges arising after a person dies, such as arranging a funeral and managing grief. For instance, under Family Medical Leave, employees cannot remain on leave after the last day of the week in which the person dies.

The Fraser Report strengthens many of the LCO’s own findings. While he highlights innovative programs in the province, Fraser also remarks,
According to participants, families would benefit from stronger supports for anticipatory grief, loss and bereavement, including information, ongoing support groups and counselling services at all stages of care.\textsuperscript{276}

2. **Persons living in long-term care homes**

Challenges in the delivery and receiving of palliative care in long-term care homes was a pervasive theme repeated by numerous concerned individuals throughout the LCO’s consultations.

Long-term care homes are internationally recognized as an important setting for palliative care.\textsuperscript{277} While the vast majority of residents are older persons, they are also home to persons with disabilities and persons with serious health conditions that require constant access to care. As the Ontario Long Term Care Association explains,

> Nearly all (97.4\%) of people in long-term care have two or more chronic conditions that have seriously compromised their health. More than six in 10 (62\%) have Alzheimer’s disease or another dementia that has progressed to the point where they can no longer live at home or in a retirement home. Most residents are seniors, with more than half over the age of 85.\textsuperscript{278}

Long-stay residents will almost always spend their final days there, and about one third of residents die each year.\textsuperscript{279}

It is a fundamental principle of Ontario’s long-term care system that these are homes. The *Long-term Care Homes Act, 2007* (LTCHA) emphasizes that these settings must be operated in a way that respects the dignity, security, safety and comfort of their residents, and must meet not only their physical, but also their psychological, social, spiritual and cultural needs.\textsuperscript{280} Ontario’s statutory framework includes a number of provisions aimed at providing holistic supports and services to persons at this stage of life:

- For each resident, there must be a written plan of care, based on an assessment of the resident and her or his needs and preferences, and addressing all aspects including medical, nursing, personal support, social, restorative, religious and spiritual care;\textsuperscript{281}
- Every long-term care home must have a program addressing religious and spiritual practices;\textsuperscript{282}
- Homes must apply interdisciplinary approaches.\textsuperscript{283}

As mentioned before, the *Long-Term Care Homes Act, 2007* requires licensees to train all staff who provide direct care to residents on palliative care.\textsuperscript{284} Licensees also have a statutory duty under the Regulations to “ensure that every resident receives end-of-life care when required in a manner that meets their needs.”\textsuperscript{285}
Nevertheless, several stakeholders have indicated that persons residing in long-term care could benefit from an approach to care that more fully draws on and includes palliative care models.

The literature and our background consultations show that consistent, quality palliative care is not available in many long-term care homes. We heard that, despite improvements, residents’ pain and symptoms are often left untreated, transfers to hospital at the end-of-life are still too frequent, and death and dying are “hidden” rather than discussed as a normal stage in life. These concerns point to regulatory and implementation barriers in the province that, it appears, research and policy are only beginning to address.

For example, one concern raised during our consultations relates to the identification criteria for palliative care. Stakeholders informed the LCO that there is a conceptual and practical divide between care for elderly persons who are “aging into death” with serious frailties, including comorbidity and dementia, and care for those who have been diagnosed with terminal or other life-limiting illnesses. Although there are prognostic tools available to assess frailty for clinical purposes, frailty has yet to be fully incorporated into eligibility for palliative care.

Other concerns relate to the lack of precision in regulatory requirements for palliative care and implementation issues. Long-term care homes are required to ensure that legislated staffing and care standards are met, and to create written staffing plan that provides for a staffing mix that is consistent with residents’ assessed care and safety needs. However, research indicates that most homes in Ontario do not have formal palliative care strategies or programs, and staff does not receive adequate education (especially personal support workers (PSWs) who provide most front-line care). Instead, the focus of care is on daily maintenance. The LCO was informed that existing staffing levels, and performance and reporting requirements also do not account for residents’ needs nearing the end of life.

The LCO heard that, above all, such challenges result from the need for a “culture shift”. This shift would move the health care system as a whole to greater recognition of the value and importance of the long-term care system. It would also re-orient the long-term care sector itself around the recognition that residents are increasingly older, frail and vulnerable persons with very complex medical needs, who could benefit from both higher levels and different forms of care, including palliative care.

These and other difficulties addressing the needs of long-term care home residents at the end of life can be summarized as follows:

- Imprecise guidance on how regulatory requirements for palliative care should be implemented in long-term care homes’ policies, procedures and accountability.
• Lack of recognition of seriously frail individuals, including the elderly, within identification criteria for the palliative approach to care.

• As in the broader health system, attitudinal barriers to acknowledging the prevalence of death and dying.

• Insufficient staff levels and appropriate education to support care at the end of life.

• Lack of integration across long term care and health sectors.

• The need for an overall “cultural shift” based on the actual demographics of long-term care home residents.

3. Persons living in retirement homes

Retirement homes are a privately funded care setting; however, residents have varying means and are not necessarily affluent. At the same time, demand for retirement homes is increasing in part because of the lack of available space in Ontario’s long-term care sector, and due to increasingly stringent admission criteria.294 Yet retirement homes are not subject to the same level of scrutiny as long-term care homes and their residents do include vulnerable persons. As the Advocacy Centre for the Elderly (ACE) explains,

Residents of retirement homes are a potentially vulnerable group as they are often dependent on the institution that provides their care and shelter, in addition to the fact that they are ‘out of sight’ and sheltered from public scrutiny.295

The LCO has heard distressing accounts of the lack of higher level care and, specifically, palliative care in this setting. Under the Retirement Homes Act, 2010 (RHA), retirement homes need only make two care services available to residents, directly or indirectly.296 Care services are defined under the Act to encompass a wide range of services from assistance with dressing to the provision of meals.297 Therefore, unlike long-term care homes, retirement facilities can but are not required to provide palliative and end-of-life care.

Aside from any limitations on facilities themselves providing care, the LCO received further feedback from stakeholders that there are significant barriers to receiving external services in retirement homes. For instance, we heard that service providers arranged through the CCACs and palliative care providers have been refused access to residents’ apartments. Retirement homes are also known to have evicted residents when they needed palliative care. This situation has arisen while residents are living in their units and also upon their admission to hospital following a health event. Retirement homes have prohibited residents from returning home when they are discharged from hospital.298
The RHA established the Retirement Homes Regulatory Authority, which oversees standards, licensing, inspections, investigations and enforcement. Beyond this targeted legislation, retirement homes are also governed under the *Residential Tenancies Act, 2006* (RTA) because they are private tenancies. Together, this statutory regime creates rights of occupancy that are not always evident in residents’ lived experience.

Both statutes explicitly entitle residents to apply for and receive external care services of their choosing in their homes. For example, the RHA reads as follows:

**External care providers**

1. a licensee of a retirement home shall not prevent a resident of the home from applying for care services from an external provider of the resident’s choosing
2. ... a licensee of a retirement home shall not interfere with the provision of care services to a resident of the home by an external care provider.¹⁹⁹

The Bill of Rights under the same Act and the RTA contain similarly clear guarantees.³⁰⁰

However, retirement homes are permitted to apply to the Landlord and Tenant Board to evict tenants requiring “a level of care that the landlord is not able to provide”.³⁰¹ It should be noted that it is the Landlord and Tenant Board who is mandated to make the determination of whether an eviction order is appropriate; it is not at the landlord’s discretion.

Moreover, the Landlord and Tenant Board may only issue an eviction order where it is satisfied that two criteria have been met:

1. Care services provided by the retirement home *along with external services* provided in the home (such as publicly funded home and community care) must be insufficient to meet the resident’s needs
2. Appropriate alternative accommodations must be available.³⁰²

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.³⁰³

But, in practice, retirement homes do evict residents or pressure them to leave without applying to the Landlord and Tenant Board.³⁰⁴ 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. Yet, they lack access to culturally appropriate, self-determined and safe services.

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.

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

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. Initiatives that receive increased funding in these areas could, possibly, devote some funds to palliative care. 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.

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. At the same time, Ontario must deliver insured services to everyone residing in the province. Ambiguities arising from this division of power have given rise to “gaps” in care for persons living on reserve. 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. Nevertheless, jurisdictional conflicts affect the availability of palliative care, as special type of service, which we review below.

2. **Palliative care is inadequate in 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. Individuals living on reserve are eligible for provincial home and community care services as well. However, provincially funded services on reserve vary and are often not available, especially in remote communities. Indigenous peoples located or living off-reserve can generally access the same services as others in the province. 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. The MOHLTC does fund Aboriginal Health Access Centres (AHAC), which provide some palliative care on and off-reserve. But overall, Indigenous peoples’ access to palliative care is wanting.

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. 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. 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).

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. 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). 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”. 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. There are certainly efforts in Ontario to build cultural safety into care nearing the end of life. However, there is no standardized guidance on cultural safety, and Indigenous beliefs, practices and languages have not been well integrated or reinforced. 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. 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.

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.

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.  

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”. 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. 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. 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”.

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. The lack of fixed address makes standard documents a challenge and, in turn, impedes the ability to access the health system as a whole. 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. Even basic emergency services and hospital care may be beyond reach.

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. Individuals may, for instance, be unable to make or keep appointments due to the transient nature of living arrangements. Some individuals may also have difficulty obtaining prescription medications and adhering to medical advice.

Moreover, the LCO heard that homeless persons suffer considerable prejudice, which affects not only the quality of care they receive, but also has a chilling effect on their
willingness to seek out help.\textsuperscript{348} We were told that health care providers often have trouble understanding or do not support the lifestyle choices of some persons, which exacerbates the lack of contact with the health system.

Other specific difficulties arising in this area include restrictive policies around drug use in care settings for persons with addiction and, also, reliance on housing staff or social workers due to isolation from family and friends.\textsuperscript{349} But these are just a few of the impediments for this particular community.

The \textit{Declaration of Partnership} recognizes that homeless persons are marginalized and require a better government response.\textsuperscript{350} The Fraser Report also mentions homelessness and it cautions health care providers to “be flexible when delivering care to: patients who are homeless who may lack proper identification, health card or places for providers to visit...”.\textsuperscript{351} However, in Ontario, there has been little effort made to bridge the gaps that affect this particular community. Initiatives to address their needs tend to be discrete and independent projects.\textsuperscript{352}

These initiatives include “street nurses” as well as two projects that have garnered remarkably positive attention and merit at least a brief mention: the Palliative Education and Care for the Homeless (PEACH) program in Toronto, and the Mission Hospice Program in Ottawa.\textsuperscript{353}

PEACH is a community outreach program that brings palliative care to persons in various situations of homelessness through a mobile-shelter approach.\textsuperscript{354} It consists of 60 physicians as well as nurses who travel to shelters and drop-in sites to provide capacity building support to staff and direct care. The program helps persons who may have had little to no regular contact with doctors for years. It delivers early palliative care to persons no matter their stage of illness.\textsuperscript{355}

The Mission Hospice Program provides shelter-based palliative care to residents of the Ottawa Mission.\textsuperscript{356} The program uses a harm reduction approach for managing the particular needs of residents with addiction who are receiving palliative care. It seeks to reduce drug-related harm without requiring that persons with addiction stop their drug use. However, the program also has strict rules in place regarding injections at the shelter, and ensuring that medications are kept safe and administered solely by program staff.\textsuperscript{357}

In our upcoming consultations, the LCO would like to learn more about the possibilities for leveraging initiatives, such as PEACH and the Mission Hospice Program, as well as for systemic change.
6. Persons with disabilities

The community of persons with disabilities has a strong tradition of advocacy for rights to full citizenship and participation in society. The community has successfully gained recognition of various accommodations and has eliminated certain inequalities arising from societal discrimination under the Charter, Code, AODA and Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act. Yet persons with disabilities continue to advocate for the eradication of inequalities that persist in multiple areas, including care in the last stages of life.

All individuals who are nearing the end of life are in a position of vulnerability. But this vulnerability is heightened for persons with disabilities. Some elderly persons may develop physical and cognitive disability later in life and for those who experience disability prior to the onset of older age, their functional health could further decline in their later years.

The heightened vulnerability of persons with disability who are nearing death is attributable to social factors including prejudice, marginalization, social isolation and substantial experiences of abuse and neglect. Vulnerabilities are especially felt by persons with diminished cognitive capacity, who may not know their options, or face challenges communicating their needs and concerns. Unfortunately, discrimination and vulnerability serve as a barrier to quality care because they limit the ability to gain services and, sometimes, to self-advocate.

Lack of accessibility is another major barrier for persons with disabilities that affects admissions to palliative care. For instance, health providers may have difficulties identifying when persons with disabilities are nearing the end of life. Because persons with disabilities may have understudied or unpredictable illness trajectories, it can be hard to determine when a person might transition to different types of care or settings.

There are also known obstacles to the quality of care provided to persons with disabilities who actually receive services. Persons with disabilities can have complex care needs which limit the breadth of options available to them. An individual who uses a wheelchair, for example, may be restricted to facilities equipped with ramps or sufficiently wide hallways to accommodate this assistive device. Persons with disabilities that affect hearing, speech, reading, writing or comprehension may also require supports for to overcome communication barriers.

Additionally, members of this community often have pre-existing relationships with the health system that are characterized by distrust. There is a long history of paternalism toward persons with disabilities, including widespread institutionalization of those with diverse physical, cognitive and communicative abilities in Ontario and elsewhere. As a result, institutionalization is viewed as the “worst case scenario” by many who would prefer to live at home with support or in supportive housing with the addition of palliative care services.
The LCO has heard that transitions to long-term care for Ontarians with disabilities is a particularly sensitive area that merits attention. Stakeholders expressed concerns about the perception that long-term care is a form of “re-institutionalization,” that long-term care homes are often not equipped to deliver personalized care for those with complex needs, and that existing care services could be better enabled to adapt to the changing needs of persons with disabilities as they age. Some individuals are particularly underrepresented in terms of supports for independent living, such as young persons with disabilities who may not fit into a system geared toward older adults. Clearly, addressing these concerns require innovative partnerships across Ontario’s health and social care sectors.

These and other difficulties addressing the needs of persons with disabilities who are nearing the end of life can be summarized as follows:

- Lack of attention to the complex needs of persons with disabilities in the last stages of life, including accommodations in facilities and access to palliative care
- Attitudinal barriers about persons’ abilities, including their capacity for treatment decision-making
- Lack of supports for communication barriers
- Difficult relationships with the health care system arising from social discrimination, including institutionalization
- Insufficient integration across health and social sectors.

There are select initiatives in Ontario that adopt a collaborative approach to address the concerns of persons with developmental disabilities nearing the end of life. For example, the Ontario Partnership on Aging and Developmental Disabilities (OPADD) is a network of partners including the MOHLTC, Ministry of Community and Social Services (MCSS) and medical facilities. OPADD has a Transition Taskforce that works on achieving a continuum of care.371

The MOHLTC and MCSS also developed a joint protocol for persons with developmental disabilities transitioning to long-term care, called the Long-Term Care Homes Access Protocol for Adults with Developmental Disability.372 The protocol is currently being revised; however, to our knowledge it does not specifically address issues nearing the end of life, including palliative care.

As with the other communities explored in this project, we hope to learn more about further steps that might improve the dignity, participation and equality of persons with disabilities nearing the end of life.
E. Access to Justice as a Matter for Law Reform

Insofar as fostering equality and access to justice nearing the end of life is a priority for the LCO’s project, we must turn our minds to how this might be achieved, specifically, as a matter of law reform.

In this chapter, we reviewed connections between legal rights and principles, and access to services and supports. We showed that equality rights as well as other rights and principles provide a rationale for responding to Ontario’s diverse communities in a manner that respects their dignity, participation, equality and safety. (Previously in chapter 3.C, we also gave an overview of foundational laws in this area.)

Furthermore, we summarized some of the government’s prior commitments to equitable palliative care, and feedback the Province has received from stakeholders requesting that a “tailored” approach be used.

Taking into account all of these considerations, the LCO would like to know what Ontarians believe our role is in making recommendations regarding communities with unmet needs.

For instance, the LCO’s project could recommend that the Ontario government’s palliative care strategy, which is currently being formulated, adopt measures to ensure customized approaches to care for specific communities with unmet needs. This might include that any ongoing initiatives to standardize principles and eligibility criteria also account for persons who are often not identified for palliative care, such as older adults with serious frailties and persons with disabilities. We might include suggestions relating to the formal recognition of caregivers within the palliative care strategy. Among other matters, we might also propose that measures be adopted to ensure services are extended to care settings that currently struggle to provide residents with equitable care, such as group homes, shelters and long term care homes.

Another point of entry into law reform could consist of our assessing legal frameworks that affect diverse communities for their inclusion of relevant provisions concerning the last stages of life. For example, the LCO could analyze laws and policies within the provincial human rights system to determine whether they provide adequate protections for communities that are underrepresented in the health care system.

Finally, the LCO could intentionally focus on different communities to make targeted recommendations about their unique circumstances, such as caregivers, persons experiencing homelessness, First Nations, Inuit and Métis peoples or others.

Our goal in suggesting these options is to add value to reports that have already been released in this area – to take the next step in making recommendations that are responsive, concrete, precise and implementable.
At this stage of the project, we simply ask that members of the public comment on these options from a law reform perspective, so that we can refine our analysis in our consultations and, eventually, our later reports.

F. Questions for Discussion

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LAST STAGES OF LIFE

ISSUE BACKGROUNDER #2 – ACCESS FOR COMMUNITIES WITH UNMET NEEDS

What is the Last Stages of Life Project?

The Law Commission of Ontario (LCO) is Ontario’s leading law reform agency. The goal of our Improving the Last Stages of Life project is to identify and recommend law reforms in the “last stages of life.” This is a broad and inclusive term that allows us to look at rights and legal issues in end-of-life planning, palliative care, medical assistance in dying, and other issues. An important aspect of this is access for communities with unmet needs, the subject of this backgrounder. This backgrounder is one of a series of consultation documents the LCO has developed for this project.

This document is a brief overview intended to raise issues and stimulate discussion for the purposes of LCO’s consultations. This document should not be relied on as a source of law.

Why is it important to look at different communities in the last stages of life?

The issues raised in the LCO’s project affect all Ontarians because each of us dies and is affected by the deaths of those around us. But different communities have different traditions, values and expectations to the last stages of life, and thus different needs in terms of access, accommodation, information and outreach. LCO’s inclusive approach to defining care in the last stages of life means we must account for diversity in Ontario’s communities and regulatory frameworks.

We hope to learn more about these traditions, values and expectations in our consultations.

The LCO also wants to know about the views, perspectives, and values of the people and institutions who govern and implement these laws as professionals, health care agencies or institutions, government and delegated agencies. Our project strives to understand the difficulties they encounter in providing services and supports to persons who are directly affected.

Which communities are affected and what are their needs?

Recent government reviews of palliative care confirm that Ontarians suffer marked disparities in accessing quality care in the last stages of life. Changing demographics and social determinants of health such as age, disability, LGBTQ identity, Indigenous identity, income level, place of residence, mental health and culture can also strongly affect the setting, type and quality of care that Ontarians receive.
These are just a few examples of how different communities may have different needs in relation to the last stages of life:

- **Different medical conditions.** Persons with cancer receive the most publicly funded services for palliative care in Ontario (about 30%). But at least the same proportion of Canadians die from other categories of illnesses, including circulatory and respiratory diseases (about 29%). Multiple sclerosis, amyotrophic lateral sclerosis (ALS), and kidney disease are further examples of progressive illnesses that may affect fewer people, but could develop slowly, and should have access to high quality, personalized care.

- **Ontarians living with HIV.** The onset on HIV-associated neurocognitive disorders (HAND) is younger than those with Alzheimer’s disease. The disorder comes as a surprise for many and can trigger concerns for financial planning, the availability of HIV-designated services, and intersecting needs.

- **Persons living with dementia.** Among deaths due to chronic conditions in Canada, Alzheimer’s underwent the largest growth from 2000 to 2009 (growing about 25%). About 90% of persons diagnosed with dementia transition from living in the community to long-term care before their death. The important process of health care consent and advance care planning has thus been identified in our project as an important area of the law for this community of Ontarians to better ensure values, beliefs and wishes are made aware.

- **Caregivers.** At some point in life, most Ontarians act as a caregiver to a family member or friend. Up to 75% of care in Canada is provided voluntarily by unpaid individuals and 97% of patients receiving home care in Ontario get assistance from a caregiver. Caregivers told the LCO that the time and effort required by such daily tasks can be incredibly difficult to manage without supports (such as paid benefits and respite).

- **Faith and cultural communities.** Religion and culture strongly influence beliefs and practices surrounding death for individuals, families, health care providers and communities. Faith and cultural leaders have begun to address ethical approaches to the last stages of life in recent years with some having delivered positions on the appropriateness of different courses of treatment, or directly providing counsel, leading prayer, mediating disputes and performing rituals after death.

- **First Nations, Inuit and Metis Communities.** Indigenous peoples are affected by shorter life expectancy, higher rates of chronic conditions and distressing health crises. 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. There is greater need for health care providers to create culturally appropriate and locally designed and controlled palliative care programs.

- **Homeless persons.** 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. Equitable and early access to effective palliative care can be a significant challenge for homeless
and vulnerably housed patients. The LCO heard that homeless persons suffer considerable prejudice, which affects not only the quality of care they receive, but also has a chilling effect on their willingness to seek out help.

- **Rural and remote communities.** Diverse communities face unique barriers accessing palliative care, such as rural and northern communities, francophone persons, cultural groups and Indigenous peoples. 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, and a lack of access to medical assistance in dying.

- **Persons with disabilities.** The heightened vulnerability of persons with disability who are nearing death is attributable to social factors including prejudice, marginalization, social isolation and substantial experiences of abuse and neglect. Vulnerabilities are especially felt by persons with diminished cognitive capacity, who may not know their options, or face challenges communicating their needs and concerns. Even where services are accessed, persons with disabilities can have complex care needs which limit the breadth of options available to them.

**Where can I get more detailed information on this topic?**

The LCO’s [Improving the Last Stages of Life Discussion Paper](https://www.lco-cdo.org/laststages) (May 2017) offers a detailed discussion of the law and practices around providing access for communities with unmet needs. Specifically, see the discussion at chapter 2.C and chapter 5.

**What kinds of questions is the LCO asking?**

The LCO has made efforts to explore how diversity influences the issues under consideration in the project. We hope to learn more about these traditions, values and expectations in our consultations:

- Within the scope of LCO’s project, are there any additional affected individuals, communities, and institutions that should be taken into account?
- What has your experience been with the last stages of life as a member or ally of a community of need?
- What law reforms do you believe are needed for communities with unmet needs, and how would such reforms be most effectively implemented in law?

**How can I share my views on this issue?**

A fuller examination of these issues is available in our [Executive Summary](https://www.lco-cdo.org/laststages) and [Discussion Paper](https://www.lco-cdo.org/laststages). We’ve also summarized other issues in a [Consultation Issues Map](https://www.lco-cdo.org/laststages) and [Issue Backgrounders](https://www.lco-cdo.org/laststages).

LCO’s formal consultation period runs from May – September 2017. The LCO invites your participation through:

- The project website at [http://www.lco-cdo.org/laststages](http://www.lco-cdo.org/laststages)
- Written submissions at any time to lawcommission@lco-cdo.org
- Watch live and archived [webcast consultation](https://www.lco-cdo.org/laststages) sessions
- Complete the [consultation survey](https://www.lco-cdo.org/laststages) on your mobile, tablet, or computer
• Propose an in-person focus group for your community
• Contacting Project Research Lawyer Ryan Fritsch through the contact information below

Law Commission of Ontario Toronto (416) 650-8406
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Written submissions will be accepted until September 29, 2017
What is the Last Stages of Life Project?

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What is the role of faith and cultural needs in the last stages of life?

Faith and culture are integral to attitudes about care nearing the end of life and perceptions of quality in health care services. While Ontario strives to improve equitable and high quality palliative care, it should consider strengthening services that reflect deeply held patient values and wishes for community engagement. As the Fraser Report explains, Ontarians have pronounced views “about the importance of ensuring that all patients have access to culturally appropriate and safe palliative and end-of-life care.”

The LCO has chosen to use the terms “faith” and “culture” for their broad scope and regular usage among stakeholders whom we consulted. We intended these terms to be inclusive of other words relevant to the issues the project reviews such as “religion”, “ethnicity”, ”ancestry” and “language”. We also acknowledge they might overlap with additional social concepts such as “race.” We further acknowledge that the LCO cannot describe examples of beliefs and practices among Ontario’s diverse communities without being reductive.

How does faith and culture influence decisions in the last stages of life?

LCO’s discussion paper examines a wide array of cultural and faith practices, and commissioned research adds to this discussion. Below, we simply highlight general ways in which faith and culture influence care for the dying. Our purpose is to identify moments when heightened attention to faith and culture is due:

- Treatment decisions: Patients and SDMs may take faith and cultural beliefs into account when making decisions about life-sustaining treatments. Some belief systems are uncomfortable with mainstream health services; others maintain that life support should be provided indefinitely.
until a person dies. Between the two, there is a spectrum of beliefs about withholding and withdrawing life support, medical assistance in dying and the receipt of non-traditional treatment.

- **Practices during illness:** Faith and cultural communities may exercise meaningful practices during illness, such as prayer and ceremonies. Practices are expressive and may require adaptive physical environments that can accommodate singing and music, smoke, prostration and visitations from community members that may exceed standardized allowances, and impact on other patients too. Practices may occur at key junctures in the illness trajectory that could require adjustments to procedural routine.

- **Significant community figures:** Community figures may embody a sense of history and collective experience. For instance, elderly persons who survived past atrocities emanating from hate and discrimination can hold special significance for community members. Family and community members might expect these figures to receive particularly respectful treatment.

- **Care for the deceased:** Caring for the deceased may involve a variety of practices, ranging from prayer to tending to the body and burial ceremonies. There may be a critical order for the succession of practices. Community members may also request to be involved in physical after-death care, and to exclude health care providers. Keeping the deceased’s body “whole” is a central belief for many faiths and cultures, which organ donation or autopsies might offend.

The above description of moments when faith and culture are engaged during the dying process is admittedly limited. Other recurring themes that the LCO heard about include food preferences, language needs and continued contact with faith and cultural peers, especially in long-term care homes.

It is also important to recognize the distinct need for “cultural safety.” This term aims to recognize 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. Thus, cultural safety involves awareness about power imbalances between health care providers and Indigenous patients, the incorporation of Indigenous understandings of death and dying, healing practices, traditional foods, spirituality, and language and cultural translation as integral to the provision of quality care.

**What is the legal framework for faith and cultural rights in the last stages of life?**

Our discussion paper goes examines Canadian and provincial law protecting faith and cultural rights. This can include the *Charter of Rights*, the *Human Rights Code*, as well as other rights and principles relevant to ensuring equality and substantive justice in health care services. Further rights and principles that could apply to faith and cultural communities stem from the Ontario Human Rights Commission 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. Faith and cultural rights are complicated by their connection with capacity and decision-making, and child protection laws.

Ontario’s health care system is also fragmented across sectors, meaning separate laws may contain various provisions relating to faith and cultural preferences. For instance, legislation governing long-
term care homes establish rights to be placed in facilities and to receive services that respond to preferences based on ethnic, spiritual, religious, linguistic, familial and cultural factors. These rights are balanced by the fact that long-term care is a group living environment, and residents frequently share rooms. Similarly, tenants in retirement homes also have a right to have their “lifestyle and choices respected and to freely pursue [their] social, cultural, religious, spiritual and other interests.” However, as retirement homes are residential tenancies, these rights may not substantially interfere with the reasonable enjoyment of the home for the licensee and other residents.

**What are some issues in supporting faith and cultural needs in practice?**

The LCO commissioned a research study that offers insights into the adequacy of faith and cultural accommodations and supports in hospitals. 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 association provide guidance, but 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. Currently in hospitals, there are few formal policies on faith and cultural issues. 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. They 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.

**Where can I get more detailed information on this topic?**

The LCO’s Improving the Last Stages of Life Discussion Paper (May 2017) discusses the law and practices around faith and cultural needs in greater depth. Specifically, see the discussion at chapter 3.C, chapter 5, and chapter 6.G. See also the expert paper commissioned by the Law Commission for this project, “Integrating religious and cultural supports into quality care in the last stages of life in Ontario.”

**What kinds of questions is the LCO asking?**

There are multiple strategies that could be used to improve culturally competent and safe care in Ontario. Possible solutions that service providers and community members spoke to LCO about include creating educational tools for cultural competence and safety. 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. 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.

- What approaches are best suited to address barriers, accommodations and supports to better integrate faith, cultural and spiritual practices into care nearing the end of life?

**How can I share my views on this issue?**

A fuller examination of these issues is available in our [Executive Summary](http://www.lco-cdo.org/laststages) and [Discussion Paper](http://www.lco-cdo.org/laststages). We’ve also summarized other issues in a [Consultation Issues Map](http://www.lco-cdo.org/laststages) and [Issue Backgrounders](http://www.lco-cdo.org/laststages).

LCO’s formal consultation period runs from May – September 2017. The LCO invites your participation through:

- The project website at [http://www.lco-cdo.org/laststages](http://www.lco-cdo.org/laststages)
- Written submissions at any time to [lawcommission@lco-cdo.org](mailto:lawcommission@lco-cdo.org)
- Watch live and archived [webcast consultation](http://www.lco-cdo.org/laststages) sessions
- Complete the [consultation survey](http://www.lco-cdo.org/laststages) on your mobile, tablet, or computer
- Propose an in-person focus group for your community
- Contacting Project Research Lawyer Ryan Fritsch through the contact information below

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**Law Commission of Ontario**

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Written submissions will be accepted until **September 29, 2017**