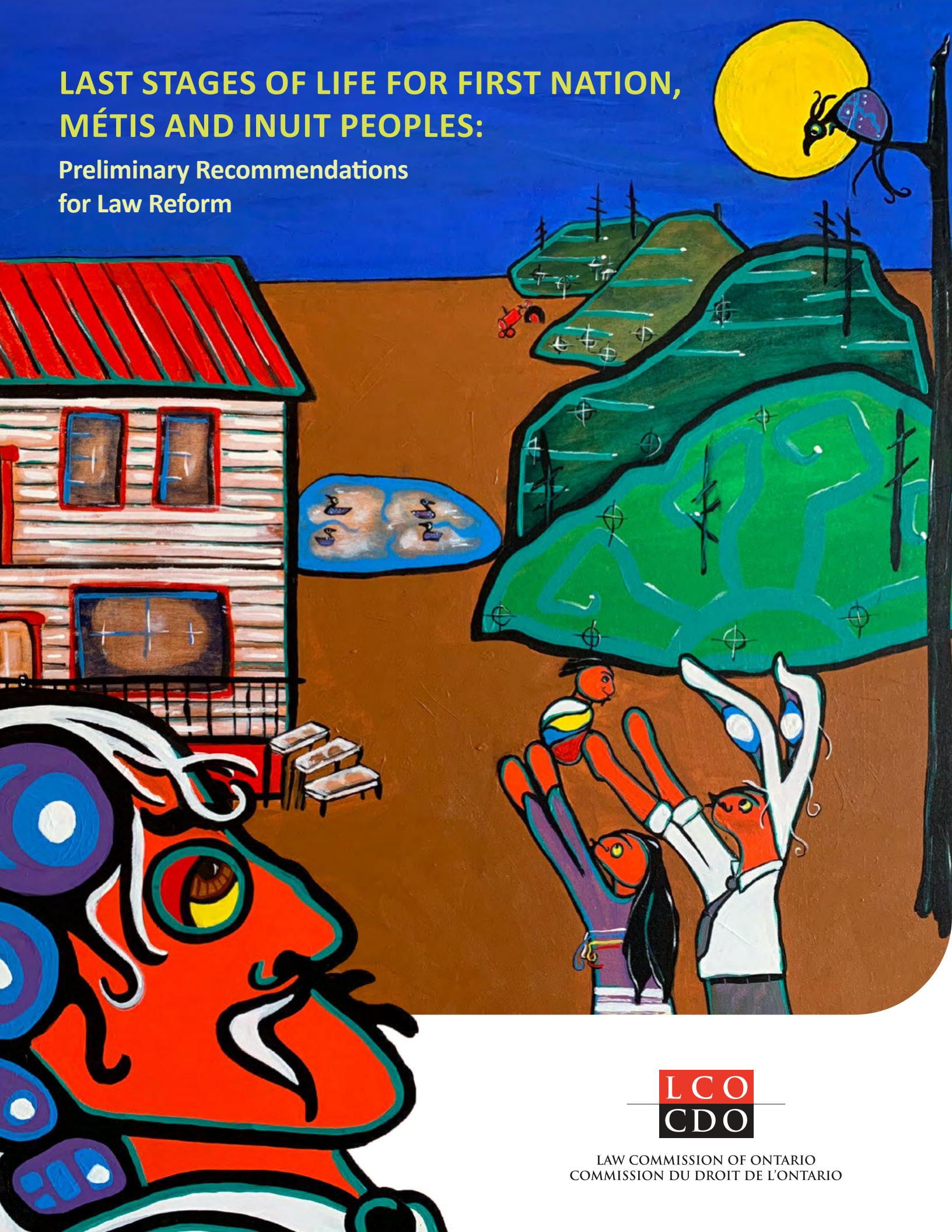


# LAST STAGES OF LIFE FOR FIRST NATION, MÉTIS AND INUIT PEOPLES:

Preliminary Recommendations  
for Law Reform



LAW COMMISSION OF ONTARIO  
COMMISSION DU DROIT DE L'ONTARIO



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The Law Commission of Ontario (LCO) is Ontario's leading law reform agency.

The LCO provides independent, balanced, and authoritative advice on complex and important legal policy issues. Through this work, the LCO promotes access to justice, evidence-based law reform and public debate. The LCO evaluates laws impartially, transparently and broadly. The LCO's analysis is informed by legal analysis; interdisciplinary research; contemporary social, demographic and economic conditions; and the impact of technology.

The LCO is located at Osgoode Hall Law School, York University, Toronto.

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## Disclaimer

The opinions or points of view expressed in the LCO’s research, findings and recommendations do not necessarily represent the views of LCO Advisory Committee members, funders (Law Foundation of Ontario, Osgoode Hall Law School, Law Society of Ontario) or supporters (Law Deans of Ontario, York University).

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This report would not have been possible without all those who gave so generously of their time, spirit, experiences, and desire to see change.

Our first steps were taken in 2018. A roundtable discussion with Indigenous chiefs, elders, health care workers, legal advocates, and health policy staff set us on a wider and deeper path of engagement over the course of a year. This would not have been possible without the guidance and dedication of the Indigenous Engagement Advisory Group. They helped keep our focus clear with their kindness, knowledge, considerable patience, and determination throughout the continuing pandemic and great personal challenges.

We also thank the 118 people who spoke to us from communities across Ontario. Each person was trusting enough to start a relationship and to discuss the very difficult issues in this report. We hope these relationships continue and deepen, and that conversations about Indigenous-lead health and community wellness gain ever more momentum.

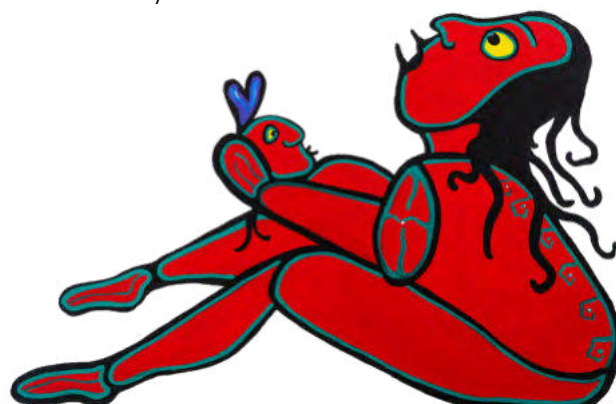
In addition, we acknowledge the contributions of Cassandra Baars, Indigenous Engagement Lead, as fundamental to building this project from the ground up and in sustaining its commitment to engage openly and meaningfully with each community we met with.

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The LCO also wishes to acknowledge our funders for this project: the Law Foundation of Ontario, the Law Society of Ontario, and Osgoode Hall Law School.

Finally, we acknowledge that this report was written during a time of pandemic. The pandemic has further disrupted Indigenous families and communities and brought illness and pain. But it also reminds us that many Indigenous health ceremonies and traditional practices include mention of pandemics. These look back in time to the effect of colonial pandemics of the past. And they look forward in anticipation of pandemics to come. Traditional knowledge and practices are the source of much resiliency and set a path we hope this report reflects towards greater autonomy over community wellness.







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# List of Acronyms

AFN	Assembly of First Nations
AHAC	Aboriginal Health Access Centre
CCAC	Community Care Access Centre
CCB	Consent and Capacity Board
CHA	Canada Health Act
CIRNAC	Crown-Indigenous Relations and Northern Affairs Canada
COO	Chiefs of Ontario
CPSO	College of Physicians and Surgeons of Ontario
CNO	College of Nurses of Ontario
DNR	Do-Not-Resuscitate
ESA	Employment Standards Act
FNMI	First Nations, Métis and Inuit
HCCA	Health Care Consent Act
HQO	Health Quality Ontario
HPCO	Hospice Palliative Care Ontario
INAC	Indigenous and Northern Affairs Canada
ISC	Indigenous Services Canada
LCO	Law Commission of Ontario
LHIN	Local Health Integration Network
LSL	LCO Last Stages of Life Project
LSO	Law Society of Ontario
LTCHA	Long-Term Care Homes Act
MAG	Ministry of the Attorney General
MAID	Medical Assistance in Dying
MOH	Ministry of Health
NAN	Nishnawbe Aski Nation
OHIP	Ontario Health Insurance Plan
OHRC	Ontario Human Rights Commission
OPCN	Ontario Palliative Care Network
PELM	Palliative Care, End-of-Life Care, and MAID
POA	Power of Attorney (Personal Care (PC), Property (P))
SDA	Substitute Decisions Act
SDM	Substitute Decision-Maker
TRC	Truth and Reconciliation Commission of Canada
UNDRIP	United Nations Declaration on the Rights of Indigenous Peoples





**1**

**Growing Up on the Four Hills**  
by Don McIntyre

Indigenous nations provided all their teachings through story that connect us to previous generations since the beginning of time. This is where stories begin. These lessons guide us to being good humans. One such teaching, among the Anishinaabe, is the Four Hills of Life which is told generation after generation. The Four Hills express our journey through this life, its joys, struggles, and final outcome. This story is for my grandson Ronan. He is four years old.

When I was growing up, I lived in some undesirable areas of Toronto with my parents. Every summer, my brother, sister, and I would be sent up to the family farm near our Reservation to gather with our cousins, Grandparents, Aunties, Uncles and neighbours. Throughout the summers, we were told stories of the land, the animals, and the plants and how we were connected. We would be told stories of how the earth was created, the gift of dreaming given to humans, and our responsibilities as recipients of these gifts.

The farm was a big old house with a wooden stove in the kitchen and no plumbing. Out back, was a duck pond and our Grandpa Frank could call the ducks for supper. It was magic when they would all march single file to the fence to be fed. When we arrived at the farm each summer, my Grandpa Frank would be standing out on the dirt road to welcome us home. “Welcome home.” He would say and ask, “How are things back home?” At the end of the summer, as we were leaving to go back to the train station, he would send us off saying, “Thanks for coming home. Have a safe trip home and let us know you got home okay.” Every summer, these rituals would be repeated.

When I was about 5, my Grandpa Frank was talking with me, “Welcome home. How are things back home?” I informed him that we had moved in the Spring, and I lost my friend, and I was sad and didn’t want to talk to my parents. Grandpa Frank, sat with me on the red tractor and told me of when he was a little boy, just about my age, and had been taken to the school. When they were getting ready to take him, his Uncle told him about Four Hills we can walk, if we choose. Each of the Four Hills is like its own trade fair where you must be this big to ride the rides. The First Hill had babies and young kids making a game of racing



to the top. Not all made it up the First Hill. Some just gave up the race. Grandpa Frank told me when he was at the school, he didn’t see his family, and he was angry because they left him, so he didn’t want to talk to them. But he decided, that was not the hill to die on. So, he came home after grade three and loved this home. The summer ended and Grandpa Frank said “Thanks for coming home to see us. Have a safe trip home. Hope things are better when you get home, there.”

When I was about 15, my Grandpa Frank was talking with me, “Welcome home. How are things back home?” I informed him my best friend died in a car accident at the beginning of the Summer and I was angry at the people back home because they didn’t understand. Grandpa Frank leaned against the fence with me looking out at the old red tractor and told me about when he was a young man, just about my age, and had been taken to the war. When he was getting ready to enlist, his Uncle reminded him about Four Hills we can walk, if we choose. The Second Hill had many young people spreading their wings and proving their worth. Not all made it up the Second Hill. Some

just gave up the race. He told me when he was at the war, he didn't hear from his family, and he was angry because they left him, so he didn't want to talk to them. But he decided, that was not the hill to die on. So, he came home and loved this home. The summer ended and Grandpa Frank said "Thanks for coming home to see us. Have a safe trip home. Hope things are better when you get home, there."

When I was about 25, my Grandpa Frank was talking with me, "Welcome home. How are things back home?" I informed him that in the Fall, I was going away to university and leaving home for good, my family back home didn't seem to care and that made me bitter. Grandpa Frank sat on the porch with me, looking past the fence, to the remnants of the old red tractor. He told me of when he was a man, just about my age, and had decided to leave home to find a Nishqwe (woman). As he was packing up his stuff, his Uncle reminded him about Four Hills we can walk, if we choose. The Third Hill had many adult people busy with heads down and anger on their faces. Not all made it up the Third Hill. Some just gave up the race. Grandpa Frank told me when he moved away and married my Grandma, he didn't think about his family much as he was busy making a home of his own. But he decided, that was not the hill to die on. So, he came home with her and loved this home. The summer ended and Grandpa Frank said "Thanks for coming home to see us. Have a safe trip home. Hope things are better when you get home, there."

The Winter I was 32, I got a call at home that my Grandpa Frank was in the hospital, and they didn't think he would make it. I drove on bad roads with bald tires in my old Dodge Omni. I drove all night. I almost hit a moose and a coyote getting home. When I got to the hospital my Grandpa Frank was laying in the bed. He looked small. He told me he was thinking about that old red tractor and how we should get it out of the field. Then he looked at me remembering the ritual and said, "Welcome home, how are things back home?" I informed him that this was all wrong. That he couldn't leave me here alone. Grandpa Frank told me about his Uncle and the Four Hills we can walk, if we choose. The Fourth Hill had far less people. The knowledge they held in their heads had pushed the colour out of their hair, making it white. They travelled up the Fourth Hill slowly, cautiously. None could see passed the Fourth Hill. All gave up this race. Some early in the climb, some much later. Grandpa Frank told me he was happy with how he was finishing the race. I told him; I was scared for him. He smiled at me, "Thanks for coming home to see us. Have a safe trip home. Me, I'll be okay. I'm just going home."



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(c) a person described in paragraph (1)(c 1)

## 2 Introduction

## A. Engaging Indigenous Communities in Health Law Reform

This report, *The Last Stages of Life for First Nation, Métis and Inuit Peoples: Preliminary Recommendations for Law Reform*, shares findings from a series of engagements between the Law Commission of Ontario (LCO) and First Nations, Métis, and Inuit communities across Ontario, along with many who provide health services in those communities. The LCO committed to Indigenous engagement as part of our [Last Stages of Life Project](#).<sup>1</sup> The project considers how the law shapes the rights, choices, and quality of life for persons who are dying and those who support them.

### Defining “Indigenous.”

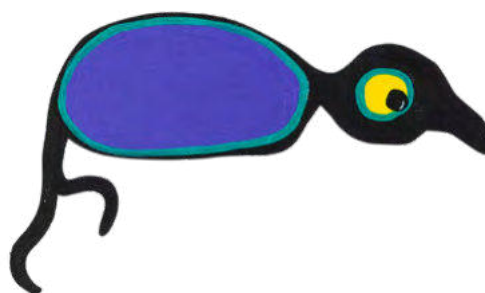
*In this report the term “Indigenous” follows the United Declaration on the Rights of Indigenous Peoples in which “Indigenous” is not defined. The Indigenous representatives of the UN Working Group 1996 stated, “We categorically reject any attempts that Governments define Indigenous Peoples.”<sup>2</sup> This favored a concept of “Indigenous” which acknowledges the right of Indigenous peoples to name themselves. “Indigenous” therefore represents a broad term that encompasses First Nation, Métis and Inuit and includes status and non-status and urban Indigenous populations. The LCO Indigenous Engagement will always respect and recognize the right of each community to name themselves.*

The LCO’s law reform project is guided by recommendations of the Truth and Reconciliation Commission of Canada.<sup>3</sup> In 2015 the TRC confirmed the need to recognize, elevate and integrate self-determined Indigenous legal orders and traditions within Canada’s justice system. The TRC states that “Aboriginal peoples must be able to recover, learn, and practice their own, distinct, legal traditions” and that “establishing respectful relations...requires the revitalization of Indigenous laws.”<sup>4</sup> This imperative acknowledges an important role for law reform in reconciliation. It exposes the relationship of the law to historical and continuing experiences of colonialism and trauma. It also denotes how things must be done differently going forward.

As an approach to law reform, it marks a significant departure from a typical project of the LCO.

Law reform projects generally develop by researching, analyzing and consulting on pre-existing law and policy.

In this project such an approach would be an imposition. It would presuppose and frame Indigenous engagement in terms of existing colonial laws. This would be the opposite of what the TRC is telling us.



- 1 Law Commission of Ontario, Last Stages of Life Website: <https://www/lco-cdo.org/laststages>. See also the Law Commission of Ontario, Indigenous Engagement Last Stages of Life Website: <https://www.lco-cdo.org/en/our-current-projects/indigenous-engagement-for-last-stages-of-life/>.
- 2 See the 1996 report of the Working Group (UN Doc. E/CN.4/Sub.2/1996/21) as follows: “We, the Indigenous Peoples present at the Indigenous Peoples Preparatory Meeting on Saturday, 27 July 1996, at the World Council of Churches, have reached a consensus on the issue of defining Indigenous Peoples and have unanimously endorsed Sub-Commission resolution 1995/32. We categorically reject any attempts that Governments define Indigenous Peoples. We further endorse the Martinez Cobo report in regard to the concept of “indigenous.” Also, we acknowledge the conclusions and recommendations by Chairperson-Rapporteur Madame Erica Daes in her working paper on the concept of indigenous peoples.”
- 3 Truth and Reconciliation Commission of Canada, Calls to Action (Winnipeg, 2015), online: [http://www.trc.ca/websites/trcinstitution/File/2015/Findings/Calls\\_to\\_Action\\_English2.pdf](http://www.trc.ca/websites/trcinstitution/File/2015/Findings/Calls_to_Action_English2.pdf) (TRC Calls to Action).
- 4 TRC Calls to Action at 205, 16.

Instead, the LCO sought respectful relations based on the revitalization of Indigenous traditions and laws. Our approach was to listen and learn how different Indigenous communities live “the last stages of life” through their experiences, values, culture, practices, and traditional laws. And how these foundations, and the experiences of communities and individuals, are dramatically (and often violently) impacted by historical and contemporary colonial institutions and laws.

This mosaic of experiences is recounted in the words spoken throughout this paper by 118 participants from Indigenous groups and communities across Ontario. Their words help establish a set of terms and approaches different and distinct from colonial law and policy. It creates space to critique, contest and de-colonize existing Canadian and Ontario law, and to think about new and different arrangements.

The LCO acknowledges that it is only from this place of Indigenous self-definition, and through the revitalization of Indigenous laws and tradition, that the reform and creation of new law is at all possible to responsibly contemplate.



Crucially, the LCO further acknowledges that it is not our role to speak for or on behalf of Indigenous communities. This report does not purport to do so. We are instead guided by the Terms of Reference set by an independent Indigenous Engagement Advisory Group.<sup>5</sup> In their view the LCO’s expertise is best suited to:

- Hear how diverse and distinct Indigenous histories, cultures, traditions, practices, and laws intersect with and experience the colonial health care system in the “last stages of life;”
- Trace these experiences back to specific provisions in colonial Canadian and Ontario health law (and other relevant intersecting laws) to understand how these laws impact the health and wellness of Indigenous communities, particularly regarding care in the last stages of life;
- Highlight how these intersections suggest plural legal and intercultural spaces for future law reform conversations to take place between Indigenous communities, Ontario, and the Federal government in a way that nurtures self-determination and legal co-creation consistent with reconciliation; and
- Compile these findings in this report which may be read alongside – but distinct from – the LCO’s *Law in the Last Stages of Life: Final Report and Recommendations*.<sup>6</sup>

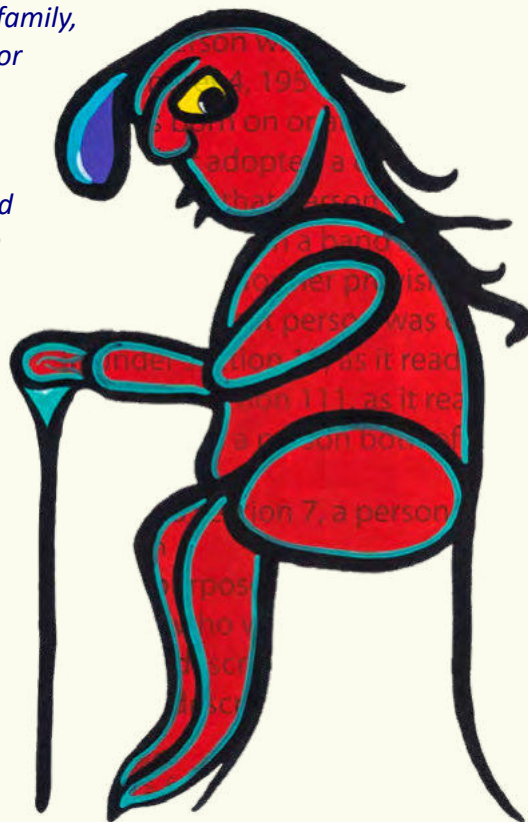
Finally, the LCO is aware that a conversation about Medical Assistance in Dying (MAID) and mental health is active and ongoing in communities across Canada. This report and the engagements does not address the intersection of mental health and MAID. More information about the scope of LCO’s review is in section 6.B.

5 These are available on the project website at <https://www.lco-cdo.org/en/our-current-projects/indigenous-engagement-for-last-stages-of-life/>.

6 Law Commission of Ontario, *Last Stages of Life Final Report: Law Reform Recommendations for Palliative Care, End-of-Life Care, and Medical Assistance in Dying* (Toronto: Law Commission of Ontario, July 2021), online: <https://www.lco-cdo.org/laststages> (LSL Final Report 2021).

## What is meant by the “last stages of life”?

*The “last stages of life” is the broad and inclusive term used in the LCO’s Last Stages of Life: Final Report (2021). It includes experiences related to palliative care, end-of-life care, and medical assistance in dying. These terms may have no settled or acceptable meaning in Indigenous communities. For some Indigenous traditions, the language of “palliative care” contradicts worldviews and makes it difficult to understand that palliative care is meant to improve quality of life with no emphasis on dying. The term “palliative care” is not used, and teachings are about “passing” into the spirit world and the strong importance of dying at home surrounded by community. In this view, end of life is a “healing process” and dying is an experience of family, community, and spirituality.<sup>7</sup> There is nothing more profound for Indigenous people than when we arrive, and when we depart. The “palliative” period may also coincide with traditional approaches to preparing for death that can be quite extensive. One example of this approach and its inherent plurality is found in *The Journey Back Home*, published by Six Nations Long-term Home & Community Care Program.<sup>8</sup> Over 44 pages it shares legends, stories and teachings about dying and death; ceremonies and traditional medicines and practices to calm and comfort the dying person; preparing for the journey with an Indian name and a personal song; beliefs on turning off life support equipment; and procedures distinguishing between different kinds of death (for example traumatic (murder), natural (old age), suicide, accident, illness/disease, miscarriage).<sup>9</sup> After death the document describes procedures for body preparation; ceremonial clothing to be worn, and how the wake and funeral are to be held; what the mourning period is and when ceremonies and feasts should occur; and shares variations in how different Haudenosaunee communities – including the Onondaga, Cayuga, Seneca, Sour Springs, and Mohawk – arrange their longhouses and funeral seating.*



- 7 Improving End-of-Life Care in First Nations Communities Research Team, Lakehead University, *Developing Palliative Care Programs in First Nations Communities: A Workbook* (Lakehead University, 2015), online: <https://eolfn.lakeheadu.ca/wp-content/uploads/2015/07/Palliative-Care-Workbook-Final-December-17.pdf> at 13 (EOLFN Palliative Workbook 2015).
- 8 Six Nations of the Grand River Territory Long-Term Care Home and Community Care Program, *For the Ones Left Behind: Coping with Grief and Loss through Traditional Ways* (Ohsweken, Ontario: 2011). See also the updated and expanded version, Six Nations of the Grand River Territory Long-Term Care Home and Community Care Program, *The Journey Back Home* (Ohsweken, Ontario: 2018) (Journey Back Home).
- 9 Journey Back Home at 5-8.



## B. The Catalyst for Health Law Reform

The LCO sought engagements on the last stages of life out of the acknowledgement that 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, an aging population, and distressing health crises.<sup>10</sup> The home and community care need of Elders and chronically ill community members have significantly increased in the last 10 years.<sup>11</sup> Several Indigenous communities have taken the step of formally declaring health emergencies.<sup>12</sup> Efforts to improve health services and community wellness are routinely undermined by fundamental inequities in access to clean water, habitable shelter, nourishing food and cultural safety.

And in the later stages of life, when many Indigenous people prefer to receive care at home and in familiar community settings, most currently die away from those communities in distant regional and urban hospitals and long-term care homes.<sup>13</sup>

The need for cultural safety is a foremost concern in these settings, and the recommendations that follow in this report must be understood in this context.

The LCO heard how the systematic displacement and eradication of Indigenous beliefs, law and ceremony in colonial health systems “has created such harm that the effort to restore cultural safety and the experiences that come as a result of that still come through the experience of racism” and is “the tension throughout the health care system.”<sup>14</sup>

Cultural safety also involves awareness about power imbalances between health care providers and Indigenous patients, and a fundamental power shift toward the patient’s experience of quality care.<sup>15</sup>

The Assembly of First Nations describes how cultural safety shifts power and control back to the patient:

*The person who receives the services defines whether it was culturally safe. This shifts the power from the provider to the person in need of the service. This is an intentional method to also understand the power imbalance that is inherent in health service delivery.*<sup>16</sup>

There is also an emerging trend, arising from existing federal and provincial law, that has begun to recognize “cultural safety” as a distinct and protected right.<sup>17</sup>

10 Ministry of Health and Long-Term Care, “Ontario Launches \$222M First Nations Action Health Plan” (2016) online: <https://news.ontario.ca/mohltc/en/2016/05/ontario-launches-222-million-first-nations-health-action-plan.html> (Ontario First Nations Health Action Plan 2016). See also National Aboriginal Health Organization “Discussion Paper on End of Life/ Palliative Care for Aboriginal Peoples” (2002), 1-7, online: [http://www.naho.ca/documents/naho/english/publications/ReB\\_palliative\\_care.pdf](http://www.naho.ca/documents/naho/english/publications/ReB_palliative_care.pdf) (NAHO 2002).

11 EOLFN Palliative Workbook 2015 at 6.

12 The Nishnawbe Aski Nation (NAN) declared a State of Health and Public Health Emergency on February 24th, 2016. NAN represents 49 First Nation communities in James Bay Treaty No. 9 and Ontario portions of Treaty No. 5 – an area covering two thirds of the province of Ontario. See: <http://www.nan.on.ca/article/health-and-public-health-emergency--2222.asp>.

13 EOLFN Palliative Workbook 2015, at 6.

14 LCO Engagement notes, Indigenous community member with legal expertise.

15 Simon Brascoupé & Catherine Water, “Cultural Safety: Exploring the Applicability of the Concept of Cultural Safety to Aboriginal Health and Community Wellness” (November 2009) 5:2 Journal of Aboriginal Health 6, at 10-13.

16 Brascoupé & Water at 16, citing Assembly of First Nations, *First Nations Cultural Safety in Post-Secondary Education* (2008) at 2.

17 The United Nations General Assembly Resolution 61/295 (September 2007), *United Nations Declaration on the Rights of Indigenous Peoples* (UNDRIP), articles 7(1), 12(1), 15(1), 21(1), 22(1), and 24 (among others) collectively support this as an Indigenous human right as well as place obligations on states to further its realization. In the health care context see also: Carrie Bourassa & Melissa Bendig, *Experiences of First Nations, Inuit and Métis People with Advanced Cancer Illness and at the End of Life: KT Tools Project Literature Review and Current State* (Winnipeg: Canadian Virtual Hospice, 2015) at 14-15.

Framing this issue as a matter of *safety* captures the relationship between mainstream services and Indigenous experiences of colonization, discrimination and oppression, which have continuing, traumatic repercussions on multiple generations.<sup>18</sup> There are efforts in Ontario to build cultural safety into care nearing the end of life.<sup>19</sup> However there is no standardized guidance on cultural safety. Indigenous beliefs, practices and languages have not been well integrated or reinforced in the health care system.<sup>20</sup>

Accordingly, Indigenous communities continue to lack access to culturally appropriate, self-determined and safe health and palliative care services.<sup>21</sup> This is despite the reality that Indigenous communities:

*Hold an enormous amount of traditional and community-based knowledge and expertise in negotiating the personal, familial, and community experiences of caring for community members who are very sick. However, through colonization, health systems have been imposed on First Nations people and western health systems typically do not support Indigenous approaches to care.*<sup>22</sup>

One First Nation expressed quite concisely what the “health care outcomes” of this imposed system are for their community:

*The current health systems that Nishnawbe Aski Nation communities currently access are not broken, they work the way that they were designed by Canada to make First Nations sicker. The outcomes of current health systems are clear; the system does not make us well but actually leads to harm of our people as patients.*<sup>23</sup>

Nowhere is this truth more apparent than in the racism faced by Indigenous people accessing health care.

In October 2020 Canadians first came to know the traumatic and extremely upsetting events culminating in the death of 37-year-old Indigenous woman Joyce Echaquan in a Joliette, Quebec hospital. She checked herself in for stomach pains but did not get the help she needed. Staff told Echaquan “she was stupid, only good for sex, and that she would be better off dead.”<sup>24</sup> Evidently in fear for her life, Echaquan’s last act was to live broadcast her treatment online in a last desperate bid for the help she needed.

18 Bourassa & Bendig at 14-15. See also Lauren Baba, *Cultural Safety in First Nations, Inuit and Métis Public Health* (Prince George, BC: National Collaborating Centre for Aboriginal Health, 2013); National Collaborating Centre for Aboriginal Health, “Cultural Safety in Healthcare”, online: [http://www.nccah-ccnsa.ca/368/Cultural\\_Safety\\_in\\_Healthcare.nccah](http://www.nccah-ccnsa.ca/368/Cultural_Safety_in_Healthcare.nccah).

19 See for instance Len Kelly and Alana Minty, “End of Life Issues of Aboriginal Patients” (2007) 53:9 *Canadian Family Physician* 1459; Len Kelly, Barb Linkewich, Natalie St Pierre-Hansen, and others, “Palliative Care of First Nations People” (2009) 55:4 *Canadian Family Physician* 394; Thunder Bay Regional Health Sciences Centre, “Aboriginal Patient Navigators Provide Support to Aboriginal Patients” (2016) online: <http://www.tbrhsc.net/aboriginal-health-at-tbrhsc/>; Joseph M. Kaufert, “Cultural Mediation in Cancer Diagnosis and End of Life Decision-Making: The Experience of Aboriginal Patients in Canada” (1999) 6:3 *Anthropology & Medicine* 405. See also: RNAO, “Embracing Cultural Diversity in Health Care: Developing Cultural Competence” (2007), online: <http://rnao.ca/bpg/guidelines/embracing-cultural-diversity-health-care-developing-cultural-competence>.

20 NAHO 2002 at 1-7.

21 NAHO 2002, 1-7; Ontario First Nations Health Action Plan 2016.

22 Holly Prince, *Supporting the Development of Palliative Care Programs in First Nations Communities: A Guide for External Partners* (Centre for Education and Research on Aging & Health, Lakehead University, 2017), online: <http://www.eikfn.lakeheadu.ca>.

23 “Health Transformation in Nishnawbe Aski Nation” (presentation of Sol Mamakwa and Ovide Mercredi AFN Health Transformation Summit Toronto, ON February 13, 2018), online: <http://www.afn.ca/wp-content/uploads/2018/03/NAN-Transformation.pdf>.

24 Mélissa Godin, “She Was Racially Abused by Hospital Staff as She Lay Dying. Now a Canadian Indigenous Woman’s Death Is Forcing a Reckoning on Racism” (*Time Magazine*: October 9, 2020), online: <https://time.com/5898422/joyce-echaquan-indigenous-protests-canada> (Godin 2020).

As reported by international media, the death of the mother of seven, a member of the Atikamekw Nation in southwestern Quebec, “sparked outrage across Canada after a summer in which protests brought systemic racism against the country’s Indigenous people to center stage.”<sup>25</sup> Prime Minister Justin Trudeau was one of many politicians to speak about Echaquan’s death, calling it the “worst form of racism.”<sup>26</sup> Quebec has publicly apologized and admitted to “failing in its duty” to Ms. Echaquan.<sup>27</sup> Her death was subsequently investigated through a coroner’s inquiry in 2021 and which confirmed that “The racism and prejudice that Mrs. Echaquan faced was certainly a contributing factor to her death.”<sup>28</sup>

Throughout LCO’s engagement we heard a distressing number of accounts of racist treatment in communities around Ontario. One Aboriginal Health Access Centre (AHAC) shared the story of a palliative Indigenous woman who was so terrified and traumatized by colonial health care institutions that she preferred to spend her last days and hours on the street. She died alone in the back alley of a downtown urban center, just a few minutes drive from a major hospital with hundreds of beds.

A recent landmark report from British Columbia illuminates the impact of endemic Indigenous racism in that province’s health care system, and how to begin addressing it.<sup>29</sup> The report engaged thousands of Indigenous people across B.C. through a survey, interviews, and written submissions. There is little reason to think similar experiences aren’t common to Ontario.

The report confirms that:

- Widespread Indigenous-specific stereotyping, racism and discrimination exist in our contemporary Canadian health care system, particularly views that Indigenous people are drug-seeking, alcoholic, and less-worthy of care;
- Racism limits access to medical treatment and primary and preventative health care, resulting in disproportionately high reliance on emergency services and hospitalization for avoidable reasons, and poorer health outcomes;
- Indigenous women and girls are disproportionately impacted by Indigenous-specific racism in the health care system, feel less safe than males in accessing care, and have poorer health outcomes than their male counterparts; and
- Indigenous health care workers face racism and discrimination in their work environments and do not feel safe reporting the racism they were experiencing or believe that such a report would create change.<sup>30</sup>

Crucial to responding to this reality is an understanding that colonial regimes do not just impose law and policy: they disrupt and displace what was pre-existing. The aim of any forward-looking law and policy reform is therefore not just to recover these pre-contact values and practices; it is to re-assert the traditional autonomy and self-determination they represent. Achieving this requires more than “working around” the barriers of colonial legacy and endemic racism: it means removing these barriers entirely.

25 Godin 2020.

26 Godin 2020.

27 CBC News, “In apology to Joyce Echaquan’s family, Quebec premier says public service “failed in its duty” (October 6, 2020), online: <https://www.cbc.ca/news/canada/montreal/joyce-echaquan-funeral-1.5752176>.

28 See Coroner of Quebec, *Investigation Report Concerning the Death of Joyce Echaquan* (September 8, 2021) at page 20, online: [https://www.coroner.gouv.qc.ca/fileadmin/Enquetes\\_publicques/2020-06375-40\\_002\\_1\\_sans\\_logo\\_anglais.pdf](https://www.coroner.gouv.qc.ca/fileadmin/Enquetes_publicques/2020-06375-40_002_1_sans_logo_anglais.pdf).

29 The Independent Investigation into Indigenous-specific Discrimination in B.C. Health Care, *In Plain Sight: Addressing Indigenous-specific Racism and Discrimination in BC Health Care* (November 2020), online: <https://engage.gov.bc.ca/addressingracism/> (In Plain Sight 2020).

30 In Plain Sight 2020, at 21, 25, 29, 33-35.

This invites thinking about ways in which the “hardwiring” of Indigenous cultural safety must be at the foundation of health care law and policy.<sup>31</sup> As recently expressed by Jody Wilson-Raybould, Canada’s former Attorney General:

*Colonialism has created a gap between Indigenous and non-Indigenous health and wellness through disempowerment and interference in Indigenous governments and legal orders. To confront this legacy... we must implement Indigenous rights, including the right to self-determination, which includes the inherent right of self-government. This means Indigenous peoples having control over meeting the needs and well-being of their citizens under their own jurisdictions and laws. [...] If we want to address systemic racism then we have to confront the racism that remains in our institutions, as reflected in our laws, policies and practices, including the Indian Act.<sup>32</sup>*

Colonial institutions and structures are likely to receive such recommendations with apprehension. The implication of these recommendations means going beyond attempts to develop institutional “cultural competence,” a “culture of accommodation,” or programs of “shared responsibility.” These all manifest as “permitted acts” excepted from underlying colonial rules and norms. Accessing the colonial health care system necessarily includes subjugation to imposed colonial laws and governance.

Any incremental approach that does not squarely address the colonial foundation in law will struggle to conclusively remove such barriers.

Furthermore, and no less crucially, the burden in supporting incremental change is vastly and disproportionately carried by Indigenous communities themselves. Marshalling resistance and maintaining resilience in opposition to these issues is exhausting, and traumatizing, and itself cannot be sustained as an approach to incremental law reform or change.

Decolonizing the legal and policy foundation of the health care system is a daunting challenge. It would be a considerable over-reach for this report to suggest that it offers a complete roadmap to that destination. Yet tentative first steps are starting to be taken all over Canada. A serious commitment in Canada to “co-create health law” between autonomous entities – namely the governments of Canada, the provinces, territories, and Indigenous communities – is in the early and formative stages, and various initiatives underway across the country.<sup>33</sup> In 2021 the federal government codified these efforts through enactment of the *United Nations Declaration on the Rights of Indigenous Peoples Act* (UNDRIPA).<sup>34</sup> The Act requires Canada’s federal government to take all measures necessary to ensure that the laws of Canada are consistent with UNDRIP and to commence this work within three years.

31 In Plain Sight 2020, at 50.

32 In Plain Sight 2020, at 58.

33 See in particular Section 3, which looks at several examples.

34 Canada, *United Nations Declaration on the Rights of Indigenous Peoples Act* (S.C. 2021, c. 14), assented to June 21, 2021 (UNDRIPA). This debate originally took place in in 2019 when Parliament considered enactment of Bill C-262, *An Act to ensure that the laws of Canada are in harmony with the United Nations Declaration on the Rights of Indigenous Peoples*, introduced as a private members bill by Romeo Saganash (online: <https://www.parl.ca/DocumentViewer/en/42-1/bill/C-262/third-reading>). Ultimately the Bill was held up by debate in the Senate and died on the order paper when Parliament adjourned in June 2019 in preparation for the federal election that October. Debate was resumed in 2021 and royal assent was granted June 21, 2021.

Similarly, the government of British Columbia also affirmed their intention to become the first province in Canada to implement UNDRIP by enacting legislation to harmonize all provincial laws with the aims of the Declaration.<sup>35</sup>

This report should be read as an aid or starting point for conversation on these issues.

Our aim is to share what we heard in conversation with Indigenous communities about the specific ways in which colonial law plays a significant role in maintaining an entrenched set of relationships, disadvantages, and barriers to quality and self-determined care nearing the end of life for First Nations, Inuit and Métis persons in Ontario.

We heard how Ontario's health care law – and the halo of other legislation that intersects and supports it – largely reflects a colonial history and colonial values which, through the power of law, diminish, alienate, or wholly silence Indigenous culture, practices and laws that may play a role at the end of life.



To highlight a few of the many legal examples that were raised by those we spoke with, and which are discussed in greater detail later in this report:

- A significant and lifetime experience of institutional racism and trauma means some Indigenous persons do not want to, or cannot accept, health care or related guardianship and trustee services provided through non-Indigenous facilities or programs – yet they may have no other safe, legally recognized, and community-based option for seeking help or developing self-determined systems;
- Core legislation setting out health care rights to consent, the capacity to consent, patient best interests, and substitute decision-making generally excludes collective, supportive, or networked community approaches to decision-making inherent to many Indigenous communities, and which are vitally important particularly towards the end of life;
- Core legislation imposes Western values and assumptions about concepts at the end of life. Examples are a narrow conception of what “best interests” substitute decision-making looks like; a legal hierarchy of substitute decision-makers rooted in a traditional Western concept of “family;” a “standard of care” that typically excludes traditional medicines and healing practices; and even the notion of “advanced care planning” as a distasteful subject for thinking about and discussing the passing of one’s spirit to the next world;
- Health care services for chronic conditions and palliative care are often designed and measured in transactional terms with instrumental measures of success. These approaches can alienate and negate Indigenous approaches which emphasize holistic and communitarian concepts of health and wellness. Attempts at self-determining such services are frustrated by entrenched

35 British Columbia Bill 41 – 2019, *Declaration on the Rights of Indigenous Peoples Act* (2019 Legislative Session: 4th Session, 41st Parliament, enacted November 2019), online: <https://www.leg.bc.ca/parliamentary-business/legislation-debates-proceedings/41st-parliament/4th-session/bills/first-reading/gov41-1>. The legislation “requires the government to take all measures necessary to ensure the laws of British Columbia are consistent with the United Nations Declaration on the Rights of Indigenous Peoples and to prepare and implement an action plan to achieve the objectives of the Declaration.” See also “B.C. introduces legislation to align its laws, policies with United Nations’ Indigenous rights declaration” (Globe and Mail, October 24 2019), online: <https://www.theglobeandmail.com/canada/british-columbia/article-bc-tables-legislation-that-makes-it-the-first-province-to-implement/>).

administrative systems like OHIP billing codes and associated performance measures (and funding allocations) tied to Western notions of efficacy and efficiency that systematically undervalue holistic, cultural, and other community-oriented goals and measures;

- Workplace health, safety and wellness protections may not adequately account for the trauma and burnout of Indigenous health care professionals, many of whom have close and personal ties to many (or in some cases all) members of their community and their families;
- Health care facilities may be designed, built, and staffed without due consideration for accommodating practices common in, and fundamental to, many Indigenous communities, particularly in accommodating practices at the end of life. This may include smudging, the provision of traditional foods, the practice of traditional medicine, or to facilitate large, frequent or ongoing family and community gatherings at the bedside;
- Workplace supports for caregivers and family members are defined by employment and labour standards legislation that may be ignorant of cultural practices and needs in Indigenous communities. Where adolescents traditionally have the responsibility to care for those approaching death there is no provision for intermittent or long-term leave from school under education legislation, or to support adolescents more generally;
- Swift, natural, and intact burials may be confounded by unclear environmental laws, physician and coroner protocols for declaring expected deaths at home, and beliefs against autopsy;
- The distinct and growing needs of urban Indigenous populations are particularly precarious as a less visible community with fewer community supports to rely on, and who face bewildering access and eligibility issues due to poorly coordinated federal and provincial jurisdiction.

The LCO views the need to name and explore these concerns in palliative and end-of-life care not only as questions of law reform, but as the detailed work necessary to begin providing a meaningful account of health law in response to the Truth and Reconciliation Commission's (TRC) *Calls to Action*.

The *Calls to Action* list several areas for collaboration between Indigenous, federal, provincial, and territorial governments to improve health care in these circumstances. It calls upon these governments to:

*... acknowledge that Aboriginal health in Canada is a direct result of previous Canadian government policies, including residential schools, and to recognize and implement the health-care rights of Aboriginal people as identified in international law, constitutional law, and under the Treaties.<sup>36</sup>*

Additional TRC recommendations include recognizing Indigenous healing practices; increasing the number of Indigenous professionals working in health care; and providing compulsory education on Indigenous history, rights, Treaties, and practices, among others.<sup>37</sup>

Customary international law further asserts additional responsibilities on states in their relationship to Indigenous peoples. Article 21 of the *United Nations Declaration on the Rights of Indigenous Peoples* (UNDRIP) affirms that:

*Indigenous peoples have the right, without discrimination, to the improvement of their economic and social conditions, including, inter alia, in the areas of education, employment, vocational training and retraining, housing, sanitation, health and social security.<sup>38</sup>*

<sup>36</sup> TRC Calls to Action, Call 18.

<sup>37</sup> TRC Calls to Action, Calls 22, 23, 24.

<sup>38</sup> UNDRIP, Article 21.

Further articles under UNDRIP affirm that Indigenous peoples have the right:

- To determine and develop health programmes affecting them;
- To administer such programs through their own institutions;
- To traditional medicines and health practices, including conservation of vital medicinal plants, animals and minerals;
- To access, without any discrimination, to all social and health services; and
- An equal right to the enjoyment of the highest attainable standard of physical and mental health.<sup>39</sup>

These commitments call on states to take effective measures to maintain and restore the health of Indigenous peoples.<sup>40</sup> A decolonizing approach to law reform is, in the LCO's view, essential to achieving that objective.

Given the commitment of the governments of Canada and Ontario to palliative care and Indigenous health,<sup>41</sup> the LCO believes this is an opportune time to improve palliative care in a way that addresses how the law creates health inequities for Indigenous communities.

Needless to say, the LCO cannot and does not speak for Indigenous peoples. Nor do we claim to have a comprehensive account of the very diverse and individually authoritative views of different Indigenous communities throughout Ontario on matters related to dying, death, and end of life care.

But within the confines of this report we can nonetheless pursue a meaningful goal. And that is to:

- Recount the diverse and specific experiences we were told about, including traditional laws, practices, culture, and beliefs;
- Identify the common issues emerging from these experiences;
- Trace these experiences back to provisions in Canadian and Ontario health law and clarify what that law says; and
- Explore how those experiences have been shaped by law.

Naming these intersections, we believe, will assist in identifying promising directions towards the future creation of post-colonial law reform measures. These directions also have implications for what steps Ontario could take within its role and jurisdiction. Importantly, we do not aim to anticipate or direct how those conversations will proceed. Rather, the “directions” we propose are intended to identify issues or questions to help facilitate further discussions in the future. In this light, this report should be seen not as a final or definitive account of these issues but rather as a first step to inform future conversations.



<sup>39</sup> UNDRIP Articles 23, 24.

<sup>40</sup> UNDRIP Article 29.

<sup>41</sup> See, for example, the Canadian government commitment to supporting an “Indigenous-led engagement processes toward the development of a distinctions-based palliative care framework for Indigenous Peoples” in the *Framework on Palliative Care in Canada* (Health Canada: December 2018) at 28, online: <https://www.canada.ca/en/health-canada/services/health-care-system/reports-publications/palliative-care/framework-palliative-care-canada.html>). See also the Ontario First Nations Health Action Plan 2016.

## C. Who Did We Engage With and What Were the Limitations?

Outreach, engagement, and consultation are fundamental to the work of the LCO. The LCO undertakes to ensure representative participation from the many diverse voices and various groups across Ontario. More about the LCO, the scope of this project, and our approach to law reform is available in Section 6.

In this project, the LCO sought to engage with a broad array of perspectives on palliative and end-of-life care as experienced by First Nations, Métis and Inuit communities in Ontario. While acknowledging the significant legal, historical, and cultural distinctions between these nations, the LCO also acknowledged the significant distinctions within each of these nations as well.

Ontario is home to 133 First Nation communities with approximately 85.5% of living off-reserve as rural and urban Indigenous populations.<sup>42</sup> The Métis Nation of Ontario represents over 20,000 registered citizens. And at any given time, there is a community of several hundred Inuit receiving health care services (or supporting those receiving care) predominantly in and around Ottawa.

Accordingly, the LCO sought advice on how best to engage Indigenous communities to ensure that First Nation, Métis and Inuit lens applied to the LSL project. This roundtable event was convened in 2018. It confirmed that these issues are of interest and concern to Indigenous communities, and that engagement would be welcome. On that basis, roundtable participants identified two overarching goals for the project. First, to engage widely. It is important to hear from as many perspectives and experiences as possible to better understand the diversity in Indigenous traditions, law, cultures, practices and beliefs in relation to health care. And second, to identify the intersection between these traditions with colonial existing health

law and related laws. Related laws may include the impact of environmental law on natural burials; the impact of professional regulatory law on Indigenous health professionals; and the impact of guardianship law as imposing colonial government decision making for incapable persons. Examining issues such as these would, in turn, indicate potential directions for future conversations where new health law is led by local communities acting in self-determination.

The LCO accordingly sought to engage with all caregivers and family members of patients, along with the broader community members who surround and support them. This includes:

- Elders, spiritual leaders, traditional healers, and knowledge keepers;
- Indigenous and non-Indigenous nurses and physicians;
- Indigenous social workers, community care coordinators, patient navigators, translators, and program leads;
- Indigenous health centres and health service providers;
- Non-Indigenous health service providers serving Indigenous patients and families;
- Large regional hospitals, urban hospices, and Aboriginal Health Access Centres;
- Regional Indigenous groups
- Professors of Indigenous law and health care;
- Indigenous lawyers, policy leads, communities of practice; and
- Representatives from government ministries and agencies in Ontario and Nunavut, and the then Local Health Integration Networks (LHINs).

These conversations initially took place between January and June 2019. The LCO participated in 25 engagement sessions with 118 participants. These sessions comprised about 60 hours of meetings and recorded 75,000 words of notes.

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42 Ontario Federation of Indigenous Friendship Centres, *Response to the Framework on Palliative Care in Canada* (2019) at 8 (OFIFC 2019), citing Health Canada, *Framework on Palliative Care in Canada* (2018), online: <https://www.canada.ca/en/health-canada/services/health-care-system/reports-publications/palliative-care/framework-palliative-care-canada.html> (Health Canada Palliative Framework 2018).



Engagement sessions took many forms, from speaking one-on-one with individuals by phone, to in-community meetings with over a dozen participants, to interdisciplinary policy tables. Meetings would generally begin with a welcome ceremony and blessing. We would hear community stories from elders and knowledge keepers, as well as families and patients, their caregivers and medicine people, and local health care nurses and physicians. Over many hours we may share food and welcome more people to the circle. Notably, almost all of these engagements took place together, face to face, in the communities where people live.

The LCO also sought geographic diversity. We were invited to in-person visits with community members and service providers in Toronto, Thunder Bay, Six Nations, Hamilton, Ottawa, and Akwesasne. By phone we also spoke with health care administrators in Nunavut and had meetings in Toronto with representatives of the Nishnawbe Aski Nation.

In addition to these engagement sessions, the LCO also undertook an exhaustive program of legal and public policy research regarding Indigenous health law, with a focus on palliative, end-of-life care, and MAID-related initiatives, reports, and history. This included compiling and reviewing over four dozen reports, studies, strategies, workbooks, action plans, position statements and resolutions, conference proceedings, and other such documents. A selection of leading documents is included in LCO's engagement materials and remains available on our website.<sup>43</sup>

The LCO is grateful for the feedback it received over the course of the engagement period and has carefully considered every contribution in formulating this report.

Notwithstanding these efforts, the LCO must be candid about the limitations of our engagement.

The LCO acknowledges that this work reflects only a small sample of the diversity of Indigenous communities and experiences across Ontario. We also recognize that the majority of those we spoke with identify as

members of, or service providers predominantly to, First Nations communities in Ontario, both on-reserve and in urban settings. A smaller group of those we spoke with were members of, and service providers to, Inuit community members receiving care and services in and around Ottawa. Finally, engagement with the Métis Nation of Ontario was limited to conversations with a regional policy lead for health care. In some regards, this is indicative of the common challenge faced in Indigenous communities to recover and maintain Indigenous experiences, culture, laws, traditions and practices from the history of colonial oppression. As the Métis policy lead we spoke with noted:

*From a Métis perspective, we don't know what a Métis health model would look like. We assume we could adapt a First Nation model, but we haven't had conversation in our communities. This in and of itself is something that will need to be developed and communities provided with the capacity and resources to explore questions like these themselves.<sup>44</sup>*

The LCO also acknowledges the geographic and time limitations on the engagement, which ran about six months and were limited in how many communities were visited and engaged. The LCO also acknowledges that the emergence of the COVID-19 pandemic significantly extended the period between these engagements and publication of this final report. Some communities and perspectives are certain to have changed over that time. For all these reasons, the LCO reiterates that this report should be considered an aid to future conversations and not be read as a singular or comprehensive account of the issues faced by Indigenous communities or any future direction they may take.

Despite the limitations of our engagement, the LCO nonetheless believes that what we learned within the boundaries of our process is both meaningful and substantial.

43 Law Commission of Ontario, Indigenous Engagement Last Stages of Life Website: <https://www.lco-cdo.org/en/our-current-projects/indigenous-engagement-for-last-stages-of-life/>.

44 LCO Engagement notes, Métis Nation member with policy expertise.

## D. Indigenous Law Reform and Identifying Promising Directions for Future Conversations

This report does not repeat the analysis or recommendations in the LCO's *Last Stages of Life: Final Report*. That *Final Report* assessed 13 major issues and made over 50 recommendations to laws and policies affecting the last stages of life, including:

- Advance care planning and health care consent;
- Expanded Palliative Care Public Health promotion;
- Resolving health care related disputes;
- Better workplace wellness supports for health care practitioners;
- Better employment supports for caregivers; and
- Improved supports for vulnerable communities with unmet needs.

This report addresses Indigenous last stages of life. Our focus in this report is the experiences, concerns, traditional laws, practices, and cultures of Indigenous people in Ontario. In contrast to the *Last Stages of Life: Final Report*, this report does not include specific law reform recommendations. This report rather identifies “promising directions” for further discussion between the government and Indigenous communities in these matters.



As introduced above, the LCO adopted the TRC's recommendations to guide our engagement around questions of Indigenous law reform. The Indigenous Engagement Advisory Group additionally defined the goals of this project as:

*“...looking beyond the western legal order to First Nation, Métis and Inuit laws in order to learn about the diversity of Indigenous laws and practices; identify gaps and omissions within western law which would then inform Indigenous recommendations that would allow for the creation of space within existing laws and/or new laws.”<sup>45</sup>*

In this way, “The report would encompass a diversity of First Nations, Métis and Inuit (FNMI) laws and health practices for the purpose of making intercultural space that would allow for FNMI laws to apply.”<sup>46</sup>

Instead of presupposing the law we began with an open conversation that aims to give full life and breadth to Indigenous experiences, values, culture, practices, and traditional laws. This, in turn, becomes a lens through which legal and policy foundations can be questioned, discussed, untangled, and eventually re-ordered through more symmetrical and respectful engagement with Indigenous laws within Canada.<sup>47</sup> The LCO's role is to use our expertise to identify common issues emerging from these experiences; trace these experiences back to Canadian and Ontario health law; explore how Indigenous experiences have been shaped by law; and highlight what steps the province may take to foster these conversations.

45 Indigenous Engagement Advisory Group Terms of Reference, available on the Indigenous Engagement Last Stages of Life Website: <https://www.lco-cdo.org/en/our-current-projects/indigenous-engagement-for-last-stages-of-life/>.

46 Indigenous Engagement Advisory Group Terms of Reference

47 Hadley Friedland and Val Napoleon, “Gathering the Threads: Developing a Methodology for Researching and Rebuilding Indigenous Legal Tradition” (2015-2016) 1:1 Lakehead LJ 17 at 33, online: <https://www.uvic.ca/law/assets/docs/ilru/Gathering%20the%20Threads%20Lakehead%20Law%20Journal%202015%20Friedland%20Napoleon%20.pdf> (Gathering the Threads).

Accordingly, this report and the LCO's engagements were not about proposing solutions but rather identifying the issues around which future law reform discussions may take place between government and different Indigenous communities.

This is an important distinction from the "conventional" approach to law reform. The "conventional" approach inevitably means that Indigenous rights are subordinated in favor of state sovereignty through legislation. Typically, this implicitly or explicitly frames the Indigenous-state relationship in one of three ways:

- legislation that attempts to incorporate Indigenous legal concepts or principles;
- legislation that either permits or requires engagement with Indigenous laws; or
- legislation that enables limited law-making powers for Indigenous communities.<sup>48</sup>

This is not to say that law can not be – or aspire to be – equitably plural, rather that achieving such plurality requires taking a first step back from existing legislation. Law reform projects that think along conventional lines can easily narrow the scope of the legal imagination, unbalance a symmetrical relationship in favor of the colonial perspective, and construe Indigenous legal and cultural orders as "outsiders" to be accommodated. This "conventional" approach to law reform is increasingly challenged by Indigenous communities and researchers.

As one Indigenous lawyer put it:

*There's a danger in presenting Indigenous community issues as outliers from the Western system. Instead, there is a need to show the significance of that intersection in and of itself because it is equally valid... if Six Nations is the leader among many communities in what they've managed to do and the resources they've managed to harness, yet they're still feeling like they're struggling with the intersection with the Western order, imagine what this means for the other communities and rural areas. A lot of the heavy lifting to get the "interface" between community and Western order is the history of that struggle.<sup>49</sup>*

An alternative approach instead aims to foster a "co-learning environment."<sup>50</sup> This supports research and discussion about the sources and impacts of colonial law that requires "the peoples studied to participate actively in the process."<sup>51</sup> According to Julie Bull:

*...authenticity in research means employing processes that allow the researcher to learn and be responsive to an [Indigenous] mindset, which tends to be very different from a Western mindset. This enables researchers to understand and care about aspects of the specific [Indigenous] interpersonal style and concepts about self and others, rather than operating on Western assumptions about people.<sup>52</sup>*

48 Hadley Friedland, "The Role of Law Reform Agencies in Responding to the TRC Calls to Action With a Focus on: The Relationship between Indigenous Laws and Legislation" (Presentation to the Federation of Law Reform Agencies of Canada, October 12, 2018).

49 LCO Engagement notes, Indigenous community member with legal expertise.

50 Julie R. Bull, "Research with Aboriginal Peoples: Authentic Relationships as a Precursor to Ethical Research" (2010) 5:4 *Journal of Empirical Research on Human Research Ethics: An International Journal* 13 at 13 (Bull 2010).

51 Bull 2010.

52 Bull 2010 at 17.

Hadley Friedland and Val Napoleon further suggest that collaboration is also applicable when researching how Indigenous legal traditions and colonial law intersect.<sup>53</sup> For instance, as part of their ground-breaking “Accessing Justice and Reconciliation Project,” Friedland and Napoleon worked closely with Indigenous communities across Canada in a manner that avoided “idealized, romanticized, or simplified representations of Indigenous law” and did “not underestimate the impact of colonialism on Indigenous legal traditions.”<sup>54</sup> At the same time, they note how:

*...it would be misleading to suggest that all Indigenous laws are completely intact, employed formally, or even in conscious or explicit use. We are not suggesting that here. Rather, when we talk about Indigenous legal traditions at this point in history, we are necessarily talking about an undertaking that requires not just articulation and recognition, but also mindful, intentional acts of recovery and revitalization.*<sup>55</sup>

Friedland and Napoleon further underscore that Indigenous communities “do not exist or operate in complete isolation from non-Indigenous people, the justice system, or the Canadian state generally. Interconnections and interdependence exist at many levels, and it is artificial and impractical to ignore the extent of this reality.”<sup>56</sup>

To be clear, this is not a form of law reform in and of itself: it does nothing to detract from Indigenous autonomy and self-determination. Instead, the approach promotes “reflections about future research”

that can help Indigenous peoples “manag[e] the everyday legal challenges of being self-governing.”<sup>57</sup> For example, such efforts may help “to identify and articulate the Indigenous legal principles that could be accessed and applied today for the work of building strong, healthy communities now and in the future.”<sup>58</sup> As Friedland and Napoleon put it: “[T]here appears to be real potential in supporting community-based research and engagement processes to enable communities to identify and discuss legal principles, so they become more explicit and accessible within communities themselves.”<sup>59</sup>

The LCO sought to adopt these approaches in this project. In this manner, we strove to create the conditions and identify a preliminary set of issues in health (and adjacent) law which, in the words of Friedland and Napoleon, “form a solid base for a more symmetrical and respectful engagement with, and public use of, Indigenous laws within Canada.”<sup>60</sup>

The LCO believes this methodology anticipates and supports recent and future discussions between Indigenous communities and Canadian governments focused on reclaiming Indigenous autonomy over health care and health law. It also reflects the heart of the TRC Calls, UNDRIP, and anticipates conversations to come following federal enactment in 2021 *United Nations Declaration on the Rights of Indigenous Peoples Act*.<sup>61</sup> Collectively, these acknowledge and approach Indigenous communities as distinct and self-determined and not as something to be “accommodated” within existing colonial structures.

Naming the legal and policy intersections between colonial and Indigenous orders will, the LCO believes, assist in identifying promising directions towards the future creation of post-colonial law reform measures. What this report contributes to that effort is thus not a set of “final recommendations” directed particularly at government, Indigenous communities, or other organizations. The LCO’s “directions” are more appropriately understood as starting points for ongoing conversations.

53 Gathering the Threads.

54 Gathering the Threads at 19.

55 Gathering the Threads at 17.

56 Gathering the Threads at 19.

57 Gathering the Threads at 19.

58 Gathering the Threads at 41.

59 Gathering the Threads at 42.

60 Gathering the Threads at 33.

61 UNDRIPA. See also end note 34 for the legislative history.



### 3

## The Current Legal and Political Context for Indigenous Health Law Reform

## A. What are the Existing Sources of Law?

Symmetrical, self-determined, and collaborative approaches to law reform are meaningful because they open existing legal and policy foundations to reformulation. The LCO believes that opening these legal and policy foundations is crucial to situating, discussing, and eventually enacting the kinds of promising direction for health-related law reform identified in our engagement discussions, and outlined later in this paper.

There is also a renewed urgency to address these issues. In 2021 the federal government enacted the *United Nations Declaration on the Rights of Indigenous Peoples Act* (UNDRIPA).<sup>62</sup> The Act requires Canada's federal government to take all measures necessary to ensure that the laws of Canada are consistent with UNDRIP and to commence this work within three years. Similarly, the government of British Columbia also affirmed their intention to become the first province in Canada to implement UNDRIP by enacting legislation to harmonize all provincial laws with the aims of the declaration.<sup>63</sup> (See the discussion below at section 3.B.ii).

The challenge, particularly in context of Canadian health law, is the considerable complexity of that legal and policy foundation. Health care in Canada is an area of constitutionally divided jurisdiction between the federal, provincial, and territorial governments. Legal, institutional and service delivery responsibilities and divisions are not always clear and are the subject of regular constitutional litigation and administrative discord.

Further complicating this general arrangement is the “double aspect doctrine” of shared federal, provincial, and territorial responsibility for Indigenous health care. This additionally includes distinctions between First Nations, Métis, and Inuit peoples, as well as distinctions between communities within those nations.

In Ontario, Indigenous peoples receive a mix of services delivered through complicated arrangements flowing from the constitutional “double aspect” doctrine of shared federal and provincial jurisdiction, and a mix of federal, provincial and First Nations funding and services. 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 an Indigenous jurisdiction, and the geographical location and resources of distinctive Indigenous communities. This is compounded by the parameters of the “double aspect” jurisdiction with respect to end-of-life health care services, and particularly the constitutional limitations the province has in this area that the federal government does not.

The LCO anticipates that Indigenous law reform will have to take the critical step of untangling this complicated legal and policy framework for new and self-determined arrangements to be forged.

This section of the paper therefore aims to outline, if only briefly and by way of introduction, some of the key legal and policy structures currently defining health care in Indigenous communities. This includes a look at existing sources of law, namely:

- Indigenous Law;
- The Double Aspect Doctrine and Shared Jurisdiction for Health Care;
- The Empty Box, the Full Box, the Medicine Chest and UNDRIP;
- Jordan's Principle and the Canadian Human Rights Act;
- The Ontario Human Rights Code; and
- The Emergence of Cultural Safety as a Protected Right.

Additionally, this section also briefly recounts contemporary federal and provincial political developments which appear to indicate a willingness within government to engage in questions of self-determined Indigenous health care and law reform.

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62 UNDRIPA. See also end note 34 for the legislative history.

63 BC Bill 41. See end note 35 for the legislative history.

These developments include:

- Withdrawal from the Proposed Federal “Rights Framework” in Favor of the Full Box of Indigenous Rights;
- Self-Governance Agreements between Métis People and the Federal Government;
- Federal Commitments to Indigenous Health Care Reform; and
- Provincial Commitments to Health Care Reform.

## B. The Existing Sources of Law

### i. Indigenous Law and Self-Governance

Within the confines of this report it would be impossible to account for the richness and distinctiveness of traditional Indigenous teachings, beliefs, and health practices on death and dying, and of the traditional laws which govern them. Nor is it the role or mandate of the LCO to do so. What we heard in most engagement sessions is how Indigenous communities are actively recovering these traditions and laws to guide development of self-determined approaches to health and care in the last stages of life.

Importantly, the traditional foundation will be different for each community. It may also be different for each clan, community, family and individual.



One example is found in *The Journey Back Home*, published by Six Nations Long-term Home & Community Care Program.<sup>64</sup> Over 44 pages it shares legends, stories and teachings about:

- Dying and death
- Procedures for body preparation, clothing to be worn, and how the wake and funeral are to be held
- What the mourning period is and when ceremonies and feasts should occur
- Distinguishes between different kinds of death (for example traumatic (murder), natural (old age), suicide, accident, illness/disease, miscarriage), and
- Shares variations in how different Haudenosaunee communities – including the Onondaga, Cayuga, Seneca, Sour Springs, and Mohawk – arrange their longhouses and funeral seating.

*The Journey Back Home* is meant to be read as a living document that “may have different variations of correctness.”<sup>65</sup> It is also meant to be understood alongside other works, such as *Little Flower’s Sad Time*, which explores the process of explaining death to a child.<sup>66</sup>

Accounts of traditional practices demonstrate how they contribute to self-determined approaches to law reform. Traditional practices related to burial, for instance, may prescribe activities outside of Ontario’s legislation governing burials or the Coroner’s Office. Practices related to consent and best interests may have a community-wide meaning rather than individual orientation. Practices related to suicide might have no antecedent in Canada’s legislation governing medical assistance in dying, or Ontario’s implementation of that law.

64 Six Nations of the Grand River Territory Long-Term Care Home and Community Care Program, *For the Ones Left Behind: Coping with Grief and Loss through Traditional Ways* (Ohsweken, Ontario: 2011) (For the Ones Left Behind). See also the updated and expanded version, Six Nations of the Grand River Territory Long-Term Care Home and Community Care Program, *The Journey Back Home* (Ohsweken, Ontario: 2018) (The Journey Back Home).

65 Journey Back Home at 2.

66 Brenda Sandy, *Little Flower’s Sad Time*, MTS Native Services, Six Nations of the Grand River (2016).

Other sources of authority come from teachings and views that shape the traditional law of different communities. For instance, the Haudenosaunee have developed a Philosophy Statement on what constitutes the natural and harmonious world order, and how this related to the health and wellness of the people:

*Traditional philosophical principles have a crucial relevance to the challenges our people face today. Ohenton Karihwatehkwen, which means the words that come before all else, are a reminder of the place that we, as human beings, are meant to occupy in relation to all of Creation; a place of balance and respect. Our worldview comes from the Creation Story, the Original Instructions, and is expressed in our annual cycle of ceremonies of thanksgiving. Our worldview teaches us that we exist with purpose, with a sacred intent and a duty to uphold the human responsibility to all of Creation. Our core philosophy is simply expressed as one body, one mind, and one heart. In the Haudenosaunee tradition, acceptance comes from a view of the natural order that accepts and celebrates the coexistence of opposites; our purpose is contained in the quest for balance and harmony, and peace is gained by extending the respect, rights, and responsibility of family relations to other peoples. The values are the state of peacefulness, the proper way to maintain peace, and the friendship and trust needed between all things for respect to prevail. In the words that come from the Thanksgiving Address “we must see the cycle of life continue” and ensure the health and wellness of the people.”<sup>67</sup>*

Indigenous self-governance is another source of law and authority. These are formal governance structures that facilitate the administration of community, people, land and resources, institutions, and any related programs or policies. Such forms of self-government, where they exist, are very diverse and continue to evolve.

This evolution is, in part, a consequence of the *Indian Act, 1876*. It dismantled traditional systems of governance and imposed external controls on individuals and communities through a variety of means, including local “Indian agents” and the power of the federal Department of Indian Affairs. Over 100 years later Indigenous peoples saw their rights to self-government affirmed in the *Constitution Act, 1982*, and in international instruments include UNDRIP. The Royal Commission on Aboriginal Peoples (1996) further recommends recognition of the right to self-government, measures to eliminate inequities between Indigenous and non-Indigenous people in Canada, and the creation of Indigenous justice systems. They assert how:

*Establishing priorities for the use of financial resources must be done by the Aboriginal people whose lives are directly affected, in consultation with federal, provincial and territorial governments... [in] four major dimensions for social, economic and cultural initiatives:*

- *healing of individuals, families, communities and nations;*
- *improving economic opportunity and living conditions in urban and rural Aboriginal communities; developing human resources; and*
- *developing Aboriginal institutions and adapting mainstream institutions.*<sup>68</sup>

67 “Worldview: Haudenosaunee Philosophy Statement” cited in Global Institute of Psychosocial, Palliative & End-of-Life Care (GIPPEC), *A Search for Solutions: A Gathering on Palliative and End-of-Life Care for First Nations, Inuit and Metis Peoples*, at 45, online: <http://www.gippec.org/couch/uploads/file/gippec-symposium-report-2016.pdf> (GIPPEC Symposium Report 2016).

68 Royal Commission on Aboriginal Peoples, Volume 5, p 11, available online: <https://www.bac-lac.gc.ca/eng/discover/aboriginal-heritage/royal-commission-aboriginal-peoples/Pages/final-report.aspx>.



Indigenous governments may also govern healthcare programs, policies, and facilities. Some recent major initiatives are described below in section 3.C. Several sections of Section 4 of this paper further describe the experiences of Indigenous governments and health facilities.

The section below broadly outlines the relationship between federal and provincial governments to Indigenous self-governance and greater recent affirmation of “existing Aboriginal and treaty rights” (*Constitution Act* s. 35) and the inherent right of self-government within Canada.

## ii. The Empty Box, the Full Box, the Medicine Chest and UNDRIP

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 “recognizes and affirms the existing Aboriginal and treaty rights of Aboriginal peoples, that is, Indian, Inuit and Métis peoples.” Section 35 has often been referred to as an “empty box” of rights for Indigenous peoples. Section 35 acts as the “source of Canada’s inherent right to self-government policy and comprehensive land claims policy”<sup>69</sup> but is “empty” of any Indigenous rights. Conversely a “full box” of rights would “affirm First Nation’s pre-existing sovereignty, [and] needs to be reconciled with the assumed sovereignty of the Crown.”<sup>70</sup>

Discussions and debates have taken place over the last several decades on which sovereign jurisdictional and subject matter issues Canada is willing to admit to the “empty box.” First Nations have responded by calling

for support for nation rebuilding, “including law-making, institution-building, and traditional governance systems, in order to assert their inherent rights outside the purview of Canadian legislative control.”<sup>71</sup> This “full box” approach promotes “self-determination as well as jurisdiction over health, environmental protection and other matters.”<sup>72</sup>

As the “full box” approach receives increased legal recognition it would appear to deepen the legally mandated basis to engage in self-determined law reform and de-colonization of existing laws. The recent Federal Court of Canada decision *Pastion v. Dene Tha’ First Nation*, for instance, affirms that Canadian and Indigenous legal orders are, in fact, to be reconciled alongside one another:

*Indigenous legal traditions are among Canada’s legal traditions. They form part of the law of the land... [and] that aboriginal interests and customary laws were presumed to survive the assertion of sovereignty... reference to “custom” in the Indian Act must be understood in a broad sense and refers to what is more properly called Indigenous law.*<sup>73</sup>

Canadian courts and governments have recognized other sources as well, including laws and bylaws developed under *Indian Act* s. 81, pursuant to the *Family Homes on Reserves and Matrimonial Interests or Rights Act*, and various election codes, land management codes, and membership codes.<sup>74</sup>

69 “Affirming Treaty Rights and Inherent Rights, Title and Jurisdiction”, presentation of Rogers Jones to the First Nation Led Processes: Four Policies and National Building (May 1-2, 2019, online: <https://www.afn.ca/wp-content/uploads/2019/05/Affirming-Treaty-Rights-and-Inherent-Rights-Final.pptx>) (Jones 2019).

70 Jones 2019.

71 Jones 2019.

72 Jones 2019.

73 *Pastion v. Dene Tha’ First Nation* (2018 FC 648) at paras 7, 8, 13.

74 Hadley Friedland, “The Role of Law Reform Agencies in Responding to the TRC Calls to Action With a Focus on: The Relationship between Indigenous Laws and Legislation” (Presentation to the Federation of Law Reform Agencies of Canada, October 12, 2018).

Sources of health law can also find direct references in some Treaties, such as in Treaty 6, which covers Central Alberta and Saskatchewan. Treaty 6 contains a “medicine chest provision” and stipulates that medicines should be used “for the use and benefit of the Indians at the discretion of [the Indian agent].” While no such explicit language is found in any of the numbered or historical Treaties in Ontario, the Nishnawbe Aski Nation (NAN) has taken the official position that there is a treaty right, or a fiduciary duty, on the part of the Crown to provide health services for Indigenous peoples.<sup>75</sup> Other First Nation groups have also adopted the fiduciary duty to provide quality health services to Indigenous peoples.<sup>76</sup>

To some extent, progress towards affirming a “full box” of rights appears likely to continue given newly legislated commitments by both provincial and federal governments, the TRC’s *Calls to Action*, and the *United Nations Declaration on the Rights of Indigenous Peoples* (UNDRIP).

UNDRIP recognizes the inherent legal rights of Indigenous peoples, not as negotiated or granted by the jurisdiction of state entities, but rather derived “from their political, economic and social structures and from their cultures, spiritual traditions, histories and philosophies, especially their rights to their lands, territories and resources.”<sup>77</sup>

The Government of Canada endorsed UNDRIP in 2010;<sup>78</sup> ratified the international treaty in 2016 (by rescinding its objector status);<sup>79</sup> debated its enactment as Canadian law in 2019 (though unsuccessfully); and finally enacted the *United Nations Declaration on the Rights of Indigenous Peoples Act* in 2021 (UNDRIPA).<sup>80</sup> The government of British Columbia also affirmed their intention to become the first province in Canada to implement UNDRIP by enacting legislation to harmonize all provincial laws with the aims of the declaration.<sup>81</sup>

UNDRIPA requires Canada’s federal government to:

*“in consultation and cooperation with Indigenous peoples and with other federal ministers, take all measures necessary to ensure that the laws of Canada are consistent with the Declaration” and “prepare and implement an action plan to achieve the objectives of the Declaration.”<sup>82</sup>*

The national action plan is to commence in three years. This suggests that reports like this one will have a pivotal role to play in the larger strategy of aligning federal and provincial laws with the objectives of UNDRIP.

75 Nishnawbe Aski Nation, “Political Bilateral Framework on Healthcare” (Resolution 01152, March 2001), online: [http://www.sfnha.com/files/6113/9999/3848/NAN\\_01-52\\_Political\\_Bilateral\\_Framework\\_on\\_Health\\_Care.pdf](http://www.sfnha.com/files/6113/9999/3848/NAN_01-52_Political_Bilateral_Framework_on_Health_Care.pdf). NAN has also taken the position that Ontario’s LHIN structure does not uphold the First Nation treaty partnership with Ontario. They asserted rather that “LHINS reduce local control of health delivery by existing First Nation health authorities, making the system even more centralized and culturally insensitive than it already is.” See: KNet Media, “NAN Defends Treaty Rights to Health Services in Rejection of Provincial LHINs” (March 1, 2006), online: <http://media.knet.ca/node/1881>.

76 See Constance MacIntosh, “Indigenous Peoples and Health Law and Policy: Responsibilities and Obligations” in Downie 2007. A recent Supreme Court case affirmed that the Ontario government is subject to fiduciary duties in dealing with Indigenous interests in some circumstances, although the case does not speak to fiduciary duties to provide culturally safe health care. See: *Grassy Narrows First Nation v. Ontario (Natural Resources)* ([2014] 2 SCR 447) at para 50.

77 UNDRIP preamble.

78 On March 3, 2010, Canada declared that it “will take steps to endorse this aspirational document in a manner fully consistent with Canada’s Constitution and laws” (Canada, Speech from the Throne, 3 March 2010), online: <http://www.sft-ddt.gc.ca/eng/media.asp?id=1388>.

79 “Canada officially adopts UN declaration on rights of Indigenous Peoples” (CBC News, May 10, 2016), online: <https://www.cbc.ca/news/indigenous/canada-adopting-implementing-un-rights-declaration-1.3575272>.

80 UNDRIPA. See also end note 34.

81 BC BILL 41. See also end note 35.

82 UNDRIPA s. 6.

*UNDRIP sets standards for the attainment of health, involvement in determining health programs, right to traditional medicines and health practices, and the protection of culture.<sup>83</sup> UNDRIP provides an internationally recognized framework for measuring the human rights of Indigenous peoples, setting the “minimum standards for the survival, dignity and well-being of the Indigenous peoples of the world.” Several provisions squarely relate to rights associated with practicing Indigenous Spirituality.<sup>84</sup>*

### iii. The “Double Aspect” Doctrine and Shared Jurisdiction for Health Care

One of most important elements of the legal framework governing Indigenous health law is the constitutional “double aspect” doctrine of shared federal and provincial jurisdiction.

In Canada, 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 all individuals.<sup>85</sup> Key *Charter* rights to equality (s. 15) and life, liberty and security (s. 7) apply to ensure equitable access to provided healthcare,<sup>86</sup> and to ensure protection for principles of autonomy, dignity,

quality of life and the right to make decisions about one’s bodily integrity and medical care.<sup>87</sup>

The *Constitution Acts* and the *Charter* guide the construction and interpretation of the *Canada Health Act* (CHA) and through the Canada Health Transfer whereby the federal government participates in regulating health care through constitutional spending powers and funding transfers to the provinces.<sup>88</sup> Service delivery rests largely with the provinces due to their exclusive authority over hospitals (and other health institutions) and “property and civil rights”, which “has been interpreted broadly by the courts to encompass most professional services”, including health care providers.<sup>89</sup>

While the CHA establishes general parameters for provincial health insurance programs, the statute does not explicitly require the provinces to cover “extended health care services” (continuing care), which are defined in the CHA as nursing home intermediate care service, adult residential care service, home care service, and ambulatory health care service.<sup>90</sup>



<sup>83</sup> UNDRIP at Articles 21, 23, 24, 29.

<sup>84</sup> See in particular UNDRIP Articles 12(1), 25 and 34.

<sup>85</sup> *The Constitution Act, 1867* (30 & 31 Victoria, c. 3 (U.K.)); and *The Constitution Act, 1982* enacted as Schedule B to the *Canada Act 1982*, 1982, c. 11 (U.K.).

<sup>86</sup> See *Eldridge v. British Columbia (Attorney General)*, [1997] 3 SCR 624; see also discussion in the *Last Stages of Life: Discussion Paper* (May 2017), at chapter 3.C.1, online: <https://www.lco-cdo.org/wp-content/uploads/2018/06/LCO-Last-Stages-Issues-Backgrounders-1.pdf>. Extracts from that report which are more focused on Indigenous health and legal concerns are available as a standalone document, *Last Stages of Life: Discussion Paper Indigenous Extracts* (January 2019), online: <https://www.lco-cdo.org/wp-content/uploads/2020/04/LSL-Consult-Paper-Extracts-re-Indigenous-issues.pdf>.

<sup>87</sup> See *Chaoulli v. Quebec (Attorney General)*, (2005) 1 SCR 791, para. 104; *Carter v. Canada (Attorney General)*, [2015] 1 SCR 331, and discussion in LCO Discussion Paper at chapter 3.C.1.

<sup>88</sup> *Canada Health Act*, R.S.C. 1985, c. C-6 (CHA). See also William Lahey, “Medicare and the Law: Contours of an Evolving Relationship” (Lahey 2007) in Jocelyn Downie, Timothy Caulfield & Colleen Flood, eds., *Canadian Health Law and Policy* (3<sup>rd</sup> ed) (Markham, Ont.: LexisNexis Canada Inc., 2007) at 25-26 (Downie 2007).

<sup>89</sup> Lahey 2007 at 25.

<sup>90</sup> *Canada Health Act* at s. 2.

Extended services relevant to this project include palliative care in private and long-term care homes not administered by physicians, and medications outside hospital.<sup>91</sup> These services are further distinguished from conditional funding granted to the provinces to insure “medically necessary” services provided by hospitals and physicians.<sup>92</sup> Medically necessary services are not defined in standardized criteria and they vary across jurisdictions.<sup>93</sup>

There is also a separate division of shared responsibilities for funding Indigenous health care. Constitutionally in Canada the “double aspect” doctrine recognizes the power of federal and provincial legislatures to adopt valid legislation on a single subject, depending on the perspective from which the legislation is considered.<sup>94</sup> Health care is one of these areas of shared federal and provincial jurisdiction. The federal Parliament may enact laws in relation to health care under its criminal law and other powers (for example, restricting controlled drugs, decriminalizing medical assistance in dying, or prohibiting certain practices), while the provinces may legislate in relation to health care pursuant to their powers (for example over health insurance, the regulation of health professions, medical consent/decision-making, and

regulating hospitals). This is why, for example, both levels of government have roles to play in legalizing and implementing MAID.

While provincial laws of general application apply to Indigenous peoples and First Nation reserve lands in many circumstances,<sup>95</sup> several constitutional doctrines imply limits on provincial jurisdiction even in context of our current age of cooperative federalism.<sup>96</sup> Among the principles the province takes into consideration are as follows:

- **The Constitutional validity** of a proposed law as the province cannot legislate with respect to Indigenous peoples or lands reserved for First Nations. This is a consideration although the province has the jurisdiction to (and should) tailor provincial services to the Indigenous context.<sup>97</sup> The province can also legislate with respect to Indigenous peoples and lands as part of an integrated legislative scheme.<sup>98</sup>
- **The doctrine of federal paramountcy**, which renders overlapping and conflicting provincial laws inoperative to the extent of any conflict in operation with or frustration of purpose of the federal law at issue.<sup>99</sup>

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91 Section 2 of the CHA explicitly excludes nursing home intermediate care services, adult residential care services, home care services, and ambulatory health care services. For a discussion about amending the CHA to improve palliative care, see: External Panel on Options for a Legislative Response to *Carter v. Canada, Consultations on Physician-Assisted Dying: Summary of Results and Key Findings Final Report* (Government of Canada, 2015), 128-131.

92 Lahey 2007 at 25.

93 Nola Ries, “Charter Challenges” in Downie 2007 at 540. See also: Odette Madore, *The Canada Health Act: Overview and Options* (Ottawa: Parliamentary Information and Research Service of the Library of Parliament, 2005) at 8; Commission on the Future of Health Care in Canada, *Medically Necessary: What is it and who decides? Issue/Survey Paper* (July 2002); J.C. Herbert Emery & Ronald Kneebone, “The Challenge of Defining Medicare Coverage in Canada” (2013) 6:32 SPP Research Papers, University of Calgary School of Public Policy; Colleen Flood, Mark Bernard Stabile & Carolyn Hughes Tuony, *Defining the Medicare “Basket”* (Ottawa: Canadian Health Services Research Foundation, 2008).

94 In particular, the federal government has jurisdiction with respect to Indigenous peoples and lands pursuant to s. 91(24) of the *Constitution Act, 1867* and provincial governments have jurisdiction with respect to health care pursuant to ss. 92(7), (13) and (16) of the *Constitution Act, 1867*.

95 See *Cardinal v. Attorney General of Alberta* [1974] S.C.R. 695, rejecting the enclave theory of federal jurisdiction on First Nation reserve lands.

96 See the discussion in *Canadian Western Bank v. Alberta* (2007 SCC 22) at paras 60-61.

97 See e.g. *NIL/TU, O Child and Family Services Society v. B.C. Government and Service Employees’ Union* (2010 SCC 45) at para 45.

98 See e.g. *Kitkatla Band v. British Columbia (Minister of Small Business, Tourism and Culture)* (2002 SCC 31) at paras 58-75.

99 This includes First Nation band council by-laws made pursuant to the federal *Indian Act* (RSC 1985, c I-5). See the general paramountcy discussion in *Canadian Western Bank v. Alberta* (2007 SCC 22) at paras 69-75.

- **The doctrine of interjurisdictional immunity**, which prevents provincial laws from impairing the core of federal jurisdiction with respect to both Indigeneity (the “Indians” branch of s. 91(24)) and First Nation reserve land occupation and use (the “Indian lands” branch of s. 91(24), which is important when the province is involved with on reserve capital projects, such as hospitals or nursing stations).<sup>100</sup>

Importantly, none of these doctrines limit the federal government in this field. As a result, the federal government can provide health services to Indigenous people both on and off reserve pursuant to s. 91(24). It can also use the federal spending power to support such services regardless of jurisdiction – as can provincial governments – because the spending power is not subject to the constitutional division of powers.

In practice, this framework means that responsibilities and services for Indigenous peoples are complex and confusing:

- The federal government regulates and funds health care for First Nations peoples living on reserve.<sup>101</sup>
- Ontario must deliver insured services to everyone residing in the province.<sup>102</sup>
- Indigenous peoples registered under the *Indian Act*<sup>103</sup> qualify for OHIP, and off-reserve, Métis, and urban Indigenous populations are served by provincial health systems, as are First Nations people living on-reserve that are closer to urban centers and/or require complex care.<sup>104</sup>
- Federal funding on reserve is designed to cover only “essential health services,” which include home and community care, but not dedicated long-term or palliative care.<sup>105</sup>
- Individuals living on reserve are eligible for provincial home and community care services.<sup>106</sup> However, provincially funded services on reserve vary and are often not available, especially in remote communities.<sup>107</sup>

100 While this doctrine is now limited in its application, it continues to apply to s. 91(24) although some provincial laws of general application that are constitutionally inapplicable pursuant to this doctrine can nevertheless apply as federal laws if they qualify for referential incorporation into federal law pursuant to the terms of s. 88 of the federal *Indian Act*. See also *Canadian Western Bank* at paras 60 and 61; *Dick v. The Queen*, [1985] 2 S.C.R. 309.

101 Health Canada, First Nations and Inuit Health Branch, “Roles and Responsibilities”, online: <http://www.hc-sc.gc.ca/ahc-asc/branch-dirigen/fnihb-dgspni/fact-fiche-eng.php> (FNIHB Roles and Responsibilities).

102 *Health Insurance Act*, s.10.

103 *Indian Act*, RSC 1985, c 1-5.

104 Ontario Ministry of Health and Long-Term Care, “Relationship with Indigenous Communities Guideline, 2018” (January 2018), online: [http://health.gov.on.ca/en/pro/programs/publichealth/oph\\_standards/docs/protocols\\_guidelines/Relationship\\_with\\_Indigenous\\_Communities\\_Guideline\\_en.pdf](http://health.gov.on.ca/en/pro/programs/publichealth/oph_standards/docs/protocols_guidelines/Relationship_with_Indigenous_Communities_Guideline_en.pdf). Ontario is home to 133 First Nation communities – 127 of which are registered under the *Indian Act* – with approximately 85.5% of Indigenous people living off-reserve. According to the National Collaborating Centre for Aboriginal Health (NCCAHA), for off-reserve status and non-status First Nations, urban Inuit, or Métis, “the federal government plays only a limited role,” as the provinces and territories administer health services for these communities. See: OFIFC 2019 submission at 6; National Collaborating Centre for Aboriginal Health, “The State of Knowledge of Aboriginal Health: A Review of Aboriginal Public Health in Canada” (January 2012) at 66, online: <https://www.nccih.ca/docs/context/RPT-StateKnowledgeReview-EN.pdf>.

105 FNIHB Roles and Responsibilities.

106 Community Access Care Centre Client Service Policy Manual, “Eligibility Criteria for CCAC Services” online: [http://www.health.gov.on.ca/english/providers/pub/manuals/ccac/ccac\\_3.pdf](http://www.health.gov.on.ca/english/providers/pub/manuals/ccac/ccac_3.pdf)

107 Centre for Education on Aging & Health, “Provision of Palliative and End of Life Services to First Nations Communities”(2013), online: [http://eolfn.lakeheadu.ca/wp-content/uploads/2013/08/Provision\\_of\\_Palliative\\_Care\\_to\\_Ontario\\_FN\\_Communities\\_April\\_2013\\_FINAL.pdf](http://eolfn.lakeheadu.ca/wp-content/uploads/2013/08/Provision_of_Palliative_Care_to_Ontario_FN_Communities_April_2013_FINAL.pdf).

- Indigenous peoples located or living off-reserve can generally access the same services as others in the province.<sup>108</sup>
- Ontario's Ministry of Health provides funding for Aboriginal Health Access Centres (AHACs), which provide some palliative care on and off-reserve.<sup>109</sup>

While health care delivery (outside Indigenous territories) is largely a provincial matter, there are other Indigenous groups over which the federal government has responsibility to provide health care services. This includes inmates in federal penitentiaries, eligible veterans and serving members of the Canadian Forces, Inuit living within designated<sup>110</sup> (traditional) areas, and "status Indians"<sup>111</sup> (First Nations) living on reserves.

Ontario also often hears views from Indigenous peoples and organizations that the province does not have jurisdiction over certain areas, particularly on First Nation reserve lands. The Assembly of First Nations, for example, has stated that some First Nations see their Treaty relationships as being with the federal government and that Indigenous health care is "the responsibility of solely the federal government."<sup>112</sup>

This view derives, in part, from several policy initiatives over the decades that promoted health care planning and delivery as a partnership between the federal government and Indigenous communities.<sup>113</sup> This interpretation also supports the recent acceleration towards the expansion of Indigenous self-determination and self-government (such as the Nishnawbe Aski Nation (NAN) health accord, discussed below) and the enactment of UNDRIPA by the federal government.

In practice, 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., NAN) or First Nations Health Authorities.<sup>114</sup>

Outside these communities, other arrangements may prevail. The provincial Aboriginal Health Access Centres are community-led and seek to promote self-determination: 60% of their professionals are Indigenous individuals and they also employ traditional healers (for a total of 360 employees in 10 centres).<sup>115</sup>

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108 Aboriginal Health Access Centres, *Our Health, Our Seventh Generation, Our Future: 2015 Aboriginal Health Access Centres Report* (2015), at 5, online: <https://www.aohc.org/sites/default/files/documents/2015%20AHAC%20Report%20-%20Copy.pdf> (AHAC 2015).

109 AHAC 2015 at 11.

110 Federal responsibility with respect to providing health care and services to Inuit is limited to those registered with and recognized by one of the four Inuit land claim organizations/agreements: Nunavik [The James Bay and Northern Quebec Agreement (1975) and The Nunavik Inuit Land Claims Agreement (2005)], Inuvialuit Settlement Region [Inuvialuit Final Agreement (1984)], Nunavut [Nunavut Land Claims Agreement (1999)], and Nunatsiavut [Labrador Inuit Land Claims Agreement (2005)]. See Health Canada, "Your Health Benefits—A Guide for Inuit to Access Non-Insured Health Benefits (March 2020), online: <https://www.sac-isc.gc.ca/eng/1585310583552/1585310609830>.

111 This is a Government of Canada term to represent First Nations peoples who are registered on the "Indian Register" under the *Indian Act*, RSC 1985, c I-5.

112 See the discussion in this paper at Section 3.B.iv and Section 4.D, "The Impact of Jurisdiction on Jordan's Principle and Equitable Access to Health Care."

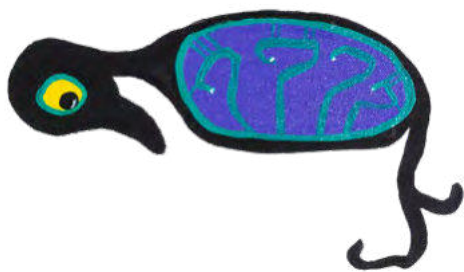
113 Indeed, it was back in 1979 that the federal government developed its Indian Health Policy (IHP) with the goal "to achieve an increasing level of health in Indian communities, generated and maintained by the Indian communities themselves (see: Indigenous Services Canada, *Indian Health Policy 1979*. And since 1989, through its Health Transfer Policy (HTP) to "enable Indian Bands to design health programs, establish services and allocate funds according to community health priorities," the federal government has sought to remedy health-related disparities historically and disproportionately faced by Indigenous people compared to non-Indigenous Canadians (see: Dr. José G. Lavoie et al., *The Evaluation of the First Nations and Inuit Health Transfer Policy: Final Report: Volume 2, Report* (Winnipeg: Centre for Aboriginal Health Research, 2005) at 1.

114 See for example: Webequie First Nation, "Nursing Station" online: <http://www.webequie.ca/article/nursing-station-137.asp>; Sioux Lookout First Nation Health Authority, "About" online: <http://www.slfnha.com/>; Weeneebayko Area Health Authority, "About Us", online: <http://www.weeneebaykohealth.ca/>.

115 AHAC 2015 at 3.

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. Ambiguities arising from this division of federal and provincial power continues to give rise to “gaps” in care for persons living on reserve.<sup>116</sup> And in conjunction with views on Treaty relationships, First Nations often seek redress against the federal government for inadequate service delivery. The 2015 Auditor General of Canada’s report on *Access to Health Services for Remote First Nations Communities* recommended that “working with First Nations organizations and communities, and the provinces, Health Canada should play a key role in establishing effective coordinating mechanisms with a mandate to respond to priority health issues and related inter-jurisdictional challenges.”<sup>117</sup>

These distinctions also affect First Nations, Métis and Inuit individuals differently, since only First Nations receive federally funded services on reserve in Ontario. Although a recent Supreme Court case recognizes and affirms federal jurisdiction over Métis peoples under the *Indian Act* and s. 91(24), this recognition does not in and of itself recognize federal obligations or fiduciary duty to legislate, and consequently may or may not extend to the provision of health care.<sup>118</sup>



116 NAHO 2002 at 5, 8-9.

117 Auditor General of Canada, *Access to Health Services for Remote First Nations Communities* (2015) at para 4.131, online: [https://www.oag-bvg.gc.ca/internet/English/parl\\_oag\\_201504\\_04\\_e\\_40350.html](https://www.oag-bvg.gc.ca/internet/English/parl_oag_201504_04_e_40350.html).

118 See *Daniels v. Canada (Indian Affairs and Northern Development)* (2016 SCC 12) in which the Court expressly stated that “a finding of jurisdiction under s. 91(24) does not create a duty to legislate” (at para 15). This case is discussed in more detail later in this paper at Chapter 4.D, “The Impact of Jurisdiction on Jordan’s Principle and Equitable Access to Health Care.”

119 *First Nations Child and Family Caring Society of Canada v Attorney General of Canada* (2016 CHRT 2) (FNCFCs).

120 FNCFCs at para 364.

121 FNCFCs at para 352.

#### iv. Jordan’s Principle and the Canadian Human Rights Act

Aspects of these debates are also manifest in adjudication under the *Canadian Human Rights Act*. That Act states at s. 1.2 that it “... shall be interpreted and applied in a manner that gives due regard to First Nations legal traditions and customary laws.” Robustly interpreted, this provision anticipates how Indigenous legal traditions and customary laws may play an important part in eliminating the barriers of inequality and discrimination.

Recently, the Canadian Human Rights Tribunal recognized just such a robust interpretation in relying on “Jordan’s Principle” in their 2016 decision concerning the *First Nations Child and Family Caring Society of Canada v Attorney General of Canada*.<sup>119</sup> This establishes that the holistic and collaborative approach to continuity of health and social services applies broadly, and as a human right, that has to be proactively engaged as a shared inter- and intra-governmental responsibility.<sup>120</sup>

Jordan’s Principle is in recognition of Jordan River Anderson, a child who was born to a family of the Norway House Cree Nation in 1999. Jordan had a serious medical condition, and because of a lack of services on reserve, he was placed under provincial care to get the medical treatment he needed. After spending the first two years of his life in a hospital, he could have gone into care at a specialized foster home close to his medical facilities in Winnipeg. However, for the next two years, Aboriginal Affairs and Northern Development Canada, Health Canada and the Province of Manitoba argued over who should pay for Jordan’s foster home costs and Jordan remained in hospital. They were still arguing when Jordan passed away, at the age of five, having spent his entire life in hospital.<sup>121</sup>

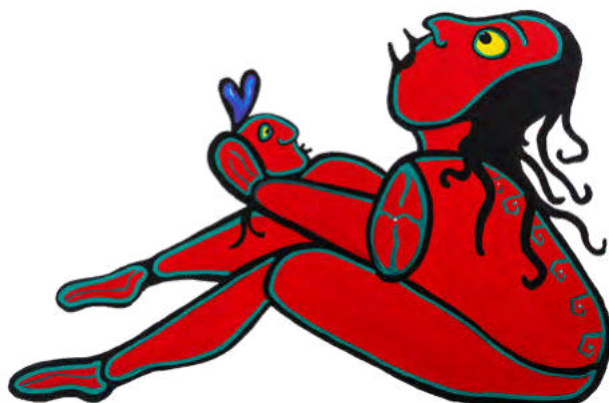
“Jordan’s Principle” therefore established that where a government service is available to all other children and a jurisdictional dispute arises between Canada and a province/territory, or between departments in the same government regarding services to a First Nations child, the government department of first contact pays for the service and resolves the jurisdictional issues later.<sup>122</sup> Jordan’s Principle subsequently became the basis for a series of agreements that committed federal departments to work collaboratively and share responsibility for implementing Jordan’s Principle. These agreements further clarify that Jordan’s Principle applies to the full range of health care and social services provided through the federal government and wherever care for children may be provided, including nursing services; home and community care; community programs; medically necessary non-insured health benefits; special education; assisted living; and income assistance.<sup>123</sup>

The CHRT’s 2016 decision further built on these developments. The Tribunal held that a narrow interpretation and inadequate implementation of Jordan’s Principle will contribute to a *prima facie* finding of discrimination under CHRA s. 5. The “full meaning and scope” of Jordan’s Principle establishes that the holistic and collaborative approach to continuity of health and social services applies broadly, and as a human right.<sup>124</sup>

Accordingly, Jordan’s Principle is now understood as:

*...a legal principle that applies to all First Nations children, ensuring that there are no gaps in government service, and recognizes that First Nations children may need government services that exceed a normative standard to ensure substantive equality, including culturally appropriate services.<sup>125</sup>*

The broader application of Jordan’s Principle has been proposed by some as calling upon the federal and provincial government to work more closely together. Notwithstanding these developments, there continues to be considerable jurisdictional tension between various levels of government. At the time this report is being written, for instance, the province of Quebec is engaged in a constitutional dispute with the federal government asserting inter-jurisdictional immunity for the provinces on certain Indigenous issues, including families and child welfare. While the case doesn’t touch on health care specifically, arguments are being heard before the Supreme Court of Canada that demonstrates how the issue remains live, in dispute, and will surely shape events to come once a decision is rendered.<sup>126</sup>



122 FNCFCs at para 351.

123 FNCFCs at para 354-355.

124 FNCFCs at paras 481-482.

125 Assembly of First Nations, “Bill C-92, Proposed Amendments submitted to the Standing Committee on Indigenous and Northern Affairs” (May 9 2019), online: [https://i1.wp.com/www.afn.ca/wp-content/uploads/2019/05/19-05-08-Bill-C-92-Proposed-Amendments\\_AFN\\_ENG-3.png](https://i1.wp.com/www.afn.ca/wp-content/uploads/2019/05/19-05-08-Bill-C-92-Proposed-Amendments_AFN_ENG-3.png).

126 See *Attorney General of Québec, et al. v. Attorney General of Canada, et al.*, Supreme Court of Canada docket #40061, online: <https://www.scc-csc.ca/case-dossier/info/dock-regi-eng.aspx?cas=40061>, on appeal from *Renvoi à la Cour d’appel du Québec relatif à la Loi concernant les enfants, les jeunes et les familles des Premières Nations, des Inuits et des Métis* (2022 QCCA 185), online: <https://canlii.ca/t/jn7nb>. See also Toronto Star, “Quebec challenge of child welfare legislation to Supreme Court expected, but Canada’s comes as a surprise” (March 22, 2022) at <https://www.thestar.com/news/canada/2022/03/22/quebec-challenge-of-child-welfare-legislation-to-supreme-court-expected-but-canadas-comes-as-a-surprise.html>.



## v. Ontario Human Rights Code

Another important legal framework influencing Indigenous last stages of life is the Ontario *Human Rights Code* (the *Code*). The Code provides similar equality protections to s.15 of the *Charter*. But while the *Charter* applies to government, the *Code* applies to both governments and the private sector, including health services and facilities. The *Code* also extends to other areas discussed in this report, including employment, housing, and contracts.

Various policies and documents issued by the Ontario Human Rights Commission (OHRC) state how equality should be interpreted under the *Code*. Some OHRC guidance documents also explicitly discuss accommodations in the health care sector.<sup>127</sup>

The Code raises several issues and questions about the relationship between Indigenous spirituality and palliative, end-of-life and MAID care. The greater concern, however, is the need for effective “protections” and whether there are enough protective thresholds that are meaningfully accessible.

For example, in the OHRC policy on creed, the *Code* is interpreted as requiring “inclusive design”, which “means being aware of differences that characterize people from *Code* protected groups when making design choices to avoid creating barriers”.<sup>128</sup>

Importantly, this policy was recently updated to acknowledge Indigenous Spirituality:

*Indigenous peoples in Ontario continue to face major barriers practicing spiritual traditions. This has sometimes been because people do not understand Indigenous Spirituality as a whole way of life, and as a result don't recognize and accommodate Indigenous Spirituality in its diverse forms and expressions. Also, attitudes and institutional practices of the colonial past continue to affect us today.*<sup>129</sup>

Notwithstanding this acknowledgement, the LCO heard several participants express a view that in practice the *Code* does not do enough to provide the conclusive guidance needed to effectively enforce protections. For example, while the Code defines the legal “duty to accommodate” when a rule or requirement negatively affects sincerely held creed beliefs and practices, neither the *Code* nor the OHRC policy define “Indigenous Spirituality.” Nor does the Code or OHRC recognize Indigenous peoples’ right to define and determine the contours of Indigenous Spirituality for themselves.

This can act as a barrier to recognition and accommodation, which leads to discrimination. Many Indigenous peoples experience systemic barriers when practicing Indigenous Spirituality.<sup>130</sup> This has been cited as the consequence of a health organizations’ narrow interpretations of what is protected under the Code ground of creed, and the failure to recognize Indigenous spiritual beliefs and practices as engaging the Code protections.<sup>131</sup>

127 See for instance the Ontario Human Rights Commission, *Policy on Preventing Discrimination Based on Creed* (2015) at chapter 11, “Indigenous spiritual practices”, online: <http://www.ohrc.on.ca/en/policy-preventing-discrimination-based-creed/11-indigenous-spiritual-practices> (OHRC Policy 2015).

128 OHRC Policy 2015.

129 OHRC Policy 2015.

130 OHRC Policy 2015.

131 OHRC Policy 2015.

## vi. Cultural Safety as a Protected Right

There is also an emerging trend arising from existing federal and provincial law that may recognize “cultural safety” as a distinct and protected right.<sup>132</sup> Framing this issue as a matter of safety captures the relationship between mainstream services and Indigenous experiences of colonization, discrimination and oppression, which have continuing, traumatic repercussions on multiple generations.<sup>133</sup> There are certainly efforts in Ontario to build cultural safety into care nearing the end of life.<sup>134</sup> However, there is no standardized guidance on cultural safety, and Indigenous beliefs, practices and languages have not been well integrated or reinforced.<sup>135</sup>

Whether culturally safe health care rises to the level of a constitutional right engages another line of inquiry. One Ontario case, *Hamilton Health Sciences vs DH*, considered whether child protection laws violate Indigenous rights, when a parent refused consent to leukemia treatment on behalf of her daughter to pursue traditional medicine.<sup>136</sup>

In that case, Ontario’s courts recognized an Indigenous right under s. 35 of the Constitution in the area of traditional healing practices and allowed for J.J.’s mother to reject treatment. However, this judgement raised serious concerns about the balance between child protection and Aboriginal rights, and the Attorney

General for Ontario became involved in a motion before the presiding judge. The judge subsequently amended his reasons stating instead that:

*...implicit in this decision is that recognition and implementation of the right to use traditional medicines must remain consistent with the principle that the best interests of the child remain paramount. The Aboriginal right to use traditional medicine must be respected, and must be considered, among other factors, in any analysis of the best interests of the child, and whether the child is in need of protection.<sup>137</sup>*

The judge went on to note that “it does no mischief to my decision to recognize that the best interests of the child remain paramount” in part because one of the core tenants of Haudenosaunee culture and society “is the ultimate respect accorded to their children. They are considered gifts from the Creator.”<sup>138</sup>

132 Carrie Bourassa & Melissa Bendig, *Experiences of First Nations, Inuit and Métis People with Advanced Cancer Illness and at the End of Life: KT Tools Project Literature Review and Current State* (Winnipeg: Canadian Virtual Hospice, 2015), at 14-15.

133 Bourassa & Bendig at 14-15. See also Lauren Baba, *Cultural Safety in First Nations, Inuit and Métis Public Health* (Prince George, BC: National Collaborating Centre for Aboriginal Health, 2013); National Collaborating Centre for Aboriginal Health, “Cultural Safety in Healthcare”, online: [http://www.nccah-ccnsa.ca/368/Cultural\\_Safety\\_in\\_Healthcare.nccah](http://www.nccah-ccnsa.ca/368/Cultural_Safety_in_Healthcare.nccah).

134 For instance: Len Kelly and Alana Minty, “End of Life Issues of Aboriginal Patients” (2007) 53:9 Canadian Family Physician 1459; Len Kelly, Barb Linkewich, Natalie St Pierre-Hansen, and others, “Palliative Care of First Nations People” (2009) 55:4 Canadian Family Physician 394; Thunder Bay Regional Health Sciences Centre, “Aboriginal Patient Navigators Provide Support to Aboriginal Patients” (2016) online: <http://www.tbrhsc.net/aboriginal-health-at-tbrhsc/>; Joseph M. Kaufert, “Cultural Mediation in Cancer Diagnosis and End of Life Decision-Making: The Experience of Aboriginal Patients in Canada” (1999) 6:3 Anthropology & Medicine 405. See also: RNAO, “Embracing Cultural Diversity in Health Care: Developing Cultural Competence” (2007), online: <http://rnao.ca/bpg/guidelines/embracing-cultural-diversity-health-care-developing-cultural-competence>.

135 NAHO 2002 at 1-7.

136 *Hamilton Health Sciences Corp v D.H* (2014 ONCJ 603) and as amended in (2015 ONCJ 229). This case is further discussed in context of substitute and best interests decision making in chapter 4.C, “Reconceiving Health Care Consent, Capacity, and Substitute Decision Making.”

137 HHS 2015 ONCJ 229, at amended para 83(a).

138 HHS 2015 ONCJ 229 at para 4.

Subsequently, the judge went on to describe how

*...the province and the family collaboratively worked to form a health care team to bring the best both had to offer to address J.J.'s ongoing treatment. This approach recognizes the province's acceptance of the family's right to practice traditional medicine and the family's acceptance western medicine will most certainly help their daughter. It is simply a recognition of what is in J.J.'s best interest. Such an approach bodes well for the future.<sup>139</sup>*

It follows from the important discussion in this case that there is an opportunity to create “culturally safe” space for Indigenous conceptions of “best interest” decision making in the course of providing health care.

The term “cultural safety” has also been coined elsewhere, including in New Zealand with respect to Maori peoples’ health care. It has developed into a way of speaking about culturally appropriate health care for Indigenous peoples around the world, including in Canada.<sup>140</sup> Generally, it aims to convey the interconnectedness of Indigenous health with the continuing repercussions of colonization, cultural and social assimilation and persisting systemic discrimination, which have led to trauma within communities and a loss of culture.<sup>141</sup> Health care that does not respond to these factors has been considered to generate “risks” to security.<sup>142</sup>

Cultural safety also involves awareness about power imbalances between health care providers and Indigenous patients, and a fundamental power shift toward the patient’s experience of quality care.<sup>143</sup>

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

*The person who receives the services defines whether it was culturally safe. This shifts the power from the provider to the person in need of the service. This is an intentional method to also understand the power imbalance that is inherent in health service delivery.<sup>144</sup>*

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

- Analyzing colonial relationships, discrimination and power imbalances
- Having service providers reflect on their own culture and its impacts on their providing care
- Understanding the pervasiveness of health problems within Indigenous communities
- Respecting the patient’s definition of what “safe” service means.<sup>145</sup>

In practice, cultural safety calls upon policymakers, service providers and communities to reformulate approaches to health care.

139 HHS 2015 ONCJ 229 at para 5.

140 Simon Brascoupé & Catherine Water, “Cultural Safety: Exploring the Applicability of the Concept of Cultural Safety to Aboriginal Health and Community Wellness” (November 2009) 5:2 *Journal of Aboriginal Health* 6.

141 Brascoupé & Water at 7.

142 Roger Walker, Helen Cromarty, Barbara Linkewich and others, “Achieving Cultural Integration in Health Services: Design of Comprehensive Hospital Model for Traditional Healing, Medicines, Foods and Supports” (January 2010) 6:1 *Journal of Aboriginal Health* 58, 59.

143 Brascoupé & Water at 10-13.

144 Brascoupé & Water at 16, citing Assembly of First Nations, *First Nations Cultural Safety in Post-Secondary Education* (2008) at 2.

145 National Collaborating Centre for Aboriginal Health, *Cultural Safety in First Nations, Inuit and Métis Public Health: Environmental Scan of Cultural Competency and Safety in Education, Training and Health Services* (Prince George, BC: National Collaborating Centre for Aboriginal Health, 2013) at 8.

## C. Recent Legal and Political Developments with Indigenous Rights

### i. Accepting the “Full Box” of Indigenous Rights

Enactment in 2021 of the federal *United Nations Declaration on the Rights of Indigenous Peoples Act* clarified that Canadian law must be interpreted consistent with the principles established in UNDRIP. Earlier but recent efforts at achieving the “full box” of Indigenous Rights nonetheless remain instructive of how challenging law reform may be going forward.

For instance, in the summer of 2019, the federal government passed legislation seen by some as beginning to “add to the empty box of s.35 rights” and acknowledging that “policies and approaches demanding the “negotiation” of inherent rights may be addressed in other ways.”<sup>146</sup> Bill C-92, *The Act to*

*Respect First Nations, Inuit and Métis Children, Youth and Families*<sup>147</sup> “affirms First Nations jurisdiction and creates space for First Nations laws and practices regarding their families.”<sup>148</sup> This includes “jurisdiction over child welfare and supports First Nations governments in developing their own systems for First Nations child welfare.”<sup>149</sup> Subsequently there are examples of communities that have now implemented their own laws.<sup>150</sup>

At the same time, however, there was continued disagreement over the extent and limits to the inherent right to self-government and the “three tiers” of sovereign jurisdictional issues which Canada was prepared to negotiate.<sup>151</sup> In response to these criticisms, which cited the government as continuing to perpetuate the “empty box” approach, Canada agreed to dispense with the proposed “rights framework.”<sup>152</sup> Instead, Canada confirmed that “federal officials would no longer require First Nations to agree to extinguish or modify their rights in exchange for a self-government

146 “Inherent Right to Self-Government”, presentation of Marlene Poitras and Kluane Adamek to the First Nation Led Processes: Four Policies and National Building (May1-2, 2019), online: <https://www.afn.ca/wp-content/uploads/2019/05/Inherent-Right-to-Self-Government-Deck-Final.pptx>.

147 Bill C-92, *An Act respecting First Nations, Inuit and Métis children, youth and families* (1<sup>st</sup> Sess, 42 Parliament, Statutes of Canada 2019 Chapter24) (assented to June 21, 2019), online: <https://www.parl.ca/DocumentViewer/en/42-1/bill/C-92/royal-assent>.

148 Assembly of First Nations, “AFN National Chief Bellegarde Says Newly Passed Legislation will Help Build Stronger and Healthier First Nations” (June 20, 2019), online: <https://www.afn.ca/afn-national-chief-bellegarde-says-newly-passed-legislation-will-help-build-stronger-and-healthier-first-nations/> (AFN 2019).

149 AFN 2019.

150 See for instance: the Coast Salish Laws Relating to Child and Caregiver Nurturance & Safety, online: <https://ilru.ca/toolkit-centres-salish-laws-on-child-caregiver-nurturance-and-safety/> and the Anishinaabeg Governance & Law Report, online: [https://ilru.ca/wp-content/uploads/2022/02/Nawendiwin\\_Report.pdf](https://ilru.ca/wp-content/uploads/2022/02/Nawendiwin_Report.pdf). Other communities which have developed laws include Saskatchewan First Nation Cowessess and in Ontario the NAN Wobseman community.

151 These “three tiers” are whether Canada negotiates openly, negotiates on the basis of Indigenous rights as subordinate to Canadian sovereign jurisdiction, or opts not to negotiate at all. See “Inherent Right to Self-Government”, presentation of Marlene Poitras and Kluane Adamek to the First Nation Led Processes: Four Policies and National Building (May1-2, 2019), online: <https://www.afn.ca/wp-content/uploads/2019/05/Inherent-Right-to-Self-Government-Deck-Final.pptx>.

152 “Carolyn Bennett backs off policy changes to modern treaty and self-government processes” (CBC News, May 2, 2019), online: <https://www.cbc.ca/news/Indigenous/carolyn-bennett-rights-policy-directive-1.5120973>). In response to the February 2018 introduction of Canada’s so-called “rights framework proposal” to replace the Comprehensive Land Claims Policy (CLCP) and Inherent Right Policy (IRP), the Assembly of First Nations issued Resolution 67 in December 2018. The Resolution rejected the “rights framework” as not First Nations led, and as continuing to perpetuate the “empty box” approach. It was characterized by some as “an attempt by Ottawa to reassert control over the ability of First Nations to move out from under Indian Act through a new policy wrapped in the language of reconciliation.” See: Assembly of First Nations (AFN) Resolution 67/2018, Rejection of the Recognition and Implementation of Indigenous Rights Framework and Associated Processes [https://www.afn.ca/wp-content/uploads/2019/01/Combined-Final-2018-December-SCA-Resolutions\\_EN.pdf](https://www.afn.ca/wp-content/uploads/2019/01/Combined-Final-2018-December-SCA-Resolutions_EN.pdf)). The AFN views this as “an opportunity for First Nations to direct the path forward to rebuild nations, implement Treaties and exert jurisdiction to develop their own laws to truly move beyond the Indian Act.” See also: First Nation Led Processes: The Four Policies and Nation Building Forum – May 2019 (May 23, 2019), online: <http://www.afn.ca/2019/05/23/first-nation-led-processes-the-four-policies-and-nation-building-forum-may-2019/>).

or modern treaty deal.”<sup>153</sup> And further confirmed that “negotiations [will] now start with a blank piece of paper and the mandate for the tables are co-developed between negotiators for both sides.”<sup>154</sup>

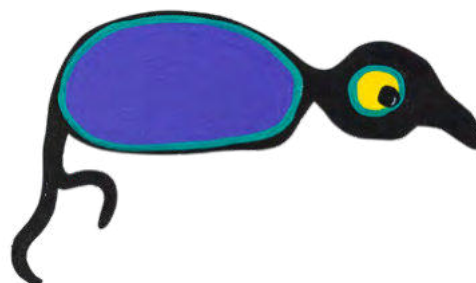
Canada now appears more eager to affirm this approach following federal elections in 2019 and 2021. In her comments before the Assembly of First Nations Annual Meeting, then Minister of Crown-Indigenous Relations Carolyn Bennett highlighted how “Our government has committed to co-develop legislation... There will only be a partnership if you feel it is a partnership. You are setting the path for decolonization and reconciliation.”<sup>155</sup> Her comments echo the direction she was given in the Minister’s Mandate Letter. That letter commits the Minister to

*...continued renewal of a nation-to-nation, Inuit-Crown and government-to-government relationship with Indigenous Peoples, advancing co-developed distinctions-based policy... advancing self-determination and, for First Nations, transitioning away from the Indian Act.*<sup>156</sup>

Similar sentiments in favor of a “full box” approach were also expressed on behalf of Canada in remarks prepared to commemorate the occasion of Canada’s ratification of UNDRIP in 2016. Minister Bennett noted that:

*By adopting and implementing the Declaration, we are excited that we are breathing life into Section 35 and recognizing it now as a full box of rights for Indigenous peoples in Canada. Canada believes that our constitutional obligations serve to fulfil all of the principles of the declaration, including free, prior and informed consent.*<sup>157</sup>

Notwithstanding the importance of these developments, some assert that even this approach may fall short of self-determined Indigenous law.<sup>158</sup> It also leaves lingering tensions and a lack of legal clarity over jurisdiction, not the least of which will be entangled provincial and federal jurisdiction if approaching health law reforms “with a blank piece of paper.”



153 “Carolyn Bennett backs off policy changes to modern treaty and self-government processes” (CBC News, May 2, 2019), online: <https://www.cbc.ca/news/Indigenous/carolyn-bennett-rights-policy-directive-1.5120973>.

154 “Carolyn Bennett backs off policy changes to modern treaty and self-government processes” (CBC News, May 2, 2019), online: <https://www.cbc.ca/news/Indigenous/carolyn-bennett-rights-policy-directive-1.5120973>.

155 CBC News, “Trudeau government moving forward on UNDRIP legislation, says minister” (December 4, 2019), online: <https://www.cbc.ca/news/Indigenous/trudeau-undrip-bill-1.5383755>.

156 Prime Minister’s Office, Mandate Letter to the Minister of Crown-Indigenous Relations (December 2019), online: <https://pm.gc.ca/en/mandate-letters/minister-crown-Indigenous-relations-mandate-letter>.

157 15th Session of the United Nations Permanent Forum on Indigenous Issues (UNPFII), “Speaking Notes for the Honourable Carolyn Bennett” (May 10, 2016), online: <http://www.northernpublicaffairs.ca/index/fully-adopting-undrip-minister-bennetts-speech/>.

158 As Neskonlith Chief Judy Wilson put it, “Overall what minister Bennett was stating today ... is still far apart from what chiefs are calling for, it’s still not co-development.” Gord Peters, Deputy Grand Chief of the Association of Iroquois and Allied Indians noted as how “When they give us something, they transform that into an Indigenous law that comes from section 35 from Canada, not us.” Both as quoted in “Carolyn Bennett backs off policy changes to modern treaty and self-government processes” (CBC News, May 2, 2019), online: <https://www.cbc.ca/news/Indigenous/carolyn-bennett-rights-policy-directive-1.5120973>.

For example, discussions providing for increased Indigenous autonomy in the autonomous design and operation of health care services squarely confronts how *Indian Act* s. 88:

*...drastically constrains jurisdictional spaces which should be filled by Indigenous sovereignty... [as] The federal government's "transfer" of legislative responsibility from itself and First Nations to provincial governments prevents First Nations from exercising self-determination... First Nations must comply with provincial laws which they have no real role in crafting or administering. In fact, if provinces were to "single out" Indians in the passage of provincial legislation such action would be ultra vires, or unconstitutional, because acting in relation to Indians is beyond provincial authority. Thus, section 88 of the Indian Act removes incentives from both the provincial and federal governments to work with Indians on the detail of laws which most effect Indian peoples' lives.<sup>159</sup>*

## ii. Métis People and Federal Government Sign First Self-Governance Agreements

The move towards greater autonomy and self-determination has also been very recently recognized in the Métis people of Canada.

In June 2019 the federal government signed the first self-governance agreements with the Métis Nation of Alberta, the Métis Nation – Saskatchewan, and the Provisional Council of the Métis Nation Ontario (MNO).

Prior to the agreement Métis nations provided some assistance in areas such as housing and employment but were not granted law-making authority or to speak on the collective behalf of Métis people.<sup>160</sup> Under the *Métis Government Recognition and Self-Government Agreement* the MNO is granted “law-making power related to certain core areas: citizenship, leadership selection, and internal governance” and provides that all MNO citizens can participate in the consultations on the Métis Government constitution including those living in Southern Ontario and the Greater Toronto Area.<sup>161</sup> Other subject matters touching on federal jurisdiction, including health and safety, are explicitly excluded from the jurisdiction of Métis Government Laws under the Agreement, though the Agreement additionally provides that at some future date the Parties “may negotiate Additional Jurisdiction Implementation Agreements in relation to the following subject matters” including “health and safety.”<sup>162</sup>

Importantly, in announcing the signing of the Agreement, then Minister Bennett characterized it as “a fundamental step to advance reconciliation and transform our relationships with the Métis Nation... [and] are committed to advancing self-determination as we strengthen our government-to-government relationships.”<sup>163</sup>

159 John Borrows, “Policy Paper: Implementing Indigenous Self-Determination Through Legislation in Canada” (April 20, 2017) at 3, online: <https://www.afn.ca/wp-content/uploads/2018/09/2017-04-20-Implementing-Indigenous-self-determination-through-policy-legislation.pdf>.

160 “Federal government signs first-ever Métis self-governance agreements” (Globe and Mail, June 27, 2019), online: <https://www.theglobeandmail.com/politics/article-federal-government-signs-first-ever-Metis-self-governance-agreements/>.

161 See *Métis Government Recognition and Self-Government Agreement between Métis Nation of Ontario and Canada* (June 2019), online: <http://www.Metisnation.org/media/655331/2019-06-27-Metis-government-recognition-and-self-government-agreement.pdf>). See also MNO, “Métis Government Recognition and Self-Government Agreement: Frequently Asked Questions”, online: <http://www.Metisnation.org/media/655314/mno-mgrsa-faq-final.pdf>).

162 *Métis Government Recognition and Self-Government Agreement between Métis Nation of Ontario and Canada* (June 2019, online: <http://www.Metisnation.org/media/655331/2019-06-27-Metis-government-recognition-and-self-government-agreement.pdf>) at Chapter 17.02 and Schedule A, “Additional Jurisdiction Implementation Agreements.”

163 Government of Canada, “Historic self-government agreements signed with the Métis Nation of Alberta, the Métis Nation of Ontario and the Métis Nation-Saskatchewan” (June 27, 2019), online: <https://www.canada.ca/en/crown-Indigenous-relations-northern-affairs/news/2019/06/historic-self-government-agreements-signed-with-the-Metis-nation-of-alberta-the-Metis-nation-of-ontario-and-the-Metis-nation-saskatchewan.html>).

### iii. Federal Commitments to Indigenous Health Care Reform

Several other federal policy and operational level reviews would further appear to support a general trend towards co-creating the law and health care programs while investing new funding into health for Indigenous communities.<sup>164</sup>

Among the leading examples are the following:

- **Passing of the *Framework on Palliative Care in Canada Act (2017)* and publication of the *Framework on Palliative Care in Canada (2018)*.**<sup>165</sup> Although the timeframe of the Framework development process did not allow for a thorough engagement process of Indigenous peoples around palliative care, Health Canada did commit to “ongoing work will include discussions between Health Canada and National Indigenous Organizations about Indigenous-led engagement processes toward the development of a distinctions-based palliative care framework for Indigenous Peoples.”<sup>166</sup> Notably, the Framework was critiqued by the Ontario Federation of Indigenous Friendship Centres for “rendering invisible the existence of a majority of the Indigenous population as well as their distinct and established urban Indigenous communities” such that the “federal government must recognize
- the *Misquadis* precedent in order to fulfill its constitutional responsibilities to all Indigenous communities in Canada regardless of legal definition.”<sup>167</sup>
- **First Nations Health Transformation Agenda (2016).** Developed under the direction of the AFN Chiefs Committee, the Agenda sets out 85 recommendations to federal, provincial, and territorial governments. These cover a wide range of policy areas all aimed at stabilizing profoundly underfunded health programs and increasing self-determination of First Nations health in keeping with inherent, Treaty and international rights.”<sup>168</sup>
- **Non-Insured Health Benefits Joint Review (2014).**<sup>169</sup> Numerous changes were implemented as a result of this review in 2016/17, including improvements to provider enrolment and claim forms, and updating the benefit policy guide to clarify eligibility of group and family counselling.<sup>170</sup> Indigenous Services Canada continues to work with Inuit representatives through the Inuit NIHB Senior Bilateral Committee (INSBC) to identify and address areas of concern and recommendations to improve the quality, access, and delivery of NIHB benefits to Inuit clients.

164 Department of Finance, “Growing the Middle Class”, *Budget 2016* (March 2016) at 143, online: <http://www.budget.gc.ca/2016/docs/plan/budget2016-en.pdf>; Ontario First Nations Health Action Plan 2016.

165 *Framework on Palliative Care in Canada Act* (S.C. 2017, c. 28) (December 2017, online: <https://laws-lois.justice.gc.ca/eng/acts/F-31.5/page-1.html>), and Health Canada, *Framework on Palliative Care in Canada* (December 2018, online: <https://www.canada.ca/en/health-canada/services/health-care-system/reports-publications/palliative-care/framework-palliative-care-canada.html#p.1.4.3>).

166 Health Canada, *Framework on Palliative Care in Canada* (December 2018, online: <https://www.canada.ca/en/health-canada/services/health-care-system/reports-publications/palliative-care/framework-palliative-care-canada.html#p.1.4.3>).

167 OFIC 2019 at 8. In *Ardoch Algonquin First Nation v. Canada (Attorney General)* (2003 FCA 473) the Federal Court of Appeal dismissed an appeal by Human Resource Development Canada in part because of their failure to consult urban and rural off-reserve Aboriginal communities and accepted the principle that non-band (urban and rural off-reserve) communities could be compared with band communities in a Charter s. 15 equality analysis.

168 Assembly of First Nations, *Health Policy Website*, online: <http://www.afn.ca/policy-sectors/health/>. See also “Getting the Relationships Right: Health Governance in the Era of Reconciliation” Report of the First Nations Health Transformation Summit (February 2018), report of January 1 2019, online: <http://www.afn.ca/wp-content/uploads/2019/06/19-01-30-Health-Summit-Report-DRAFT-V4.pdf> )

169 Assembly of First Nations, *Health Policy Website*, online: <http://www.afn.ca/policy-sectors/health/>

170 <https://www.canada.ca/en/Indigenous-services-canada/services/first-nations-inuit-health/reports-publications/non-insured-health-benefits/non-insured-health-benefits-fnihb-report-2017-2018.html>

#### iv. Provincial Commitments to Health Care Reform

There are comparatively fewer legal developments in Ontario, but several important policy and other framework agreements mark important steps forward and which may anticipate a greater role and support for co-creation of Indigenous health law reform.

Among the most significant developments in relation to this review are the following:

- **Charter of Relationship Principles Governing Health System Transformation in NAN Territory (2017).**<sup>171</sup> This multi-year trilateral agreement “marks the commitment of [the federal, provincial, and First Nations governments] to a NAN process towards health transformation” that seeks to ensure the NAN community has “equitable access to care delivered within their community” and promotes “community-based programming... and culturally safe care.”<sup>172</sup> This charter commits Ontario and Canada “to work together to address the need for a new responsive and system-wide approach to health for NAN territory... to result in immediate, medium, and long-term transformative change to the existing health system at the NAN community level.” The NAN Charter also commits to “Proposing policy reform, and considering whether legislative changes may be required, to design a new health care system for First Nations in NAN Territory that includes sustainable funding models within a new fiscal arrangement; decision
- **Ontario Palliative Care Network (OPCN) Palliative Care Health Services Delivery Framework (2019).**<sup>175</sup> The OPCN Framework acknowledged that colonialism in Canada “significantly impacted the planning, quality, access, continuity, appropriateness, and delivery of palliative care.”<sup>176</sup> The Framework proposes to adopt an approach wherein “First Nations, Inuit, Métis, and urban Indigenous patient[s] and their family/caregivers [should] receive palliative care that uses a grassroots participatory and collaborative approach and incorporates cultural knowledge into all aspects of care.”<sup>177</sup> Ten additional recommendations clarify how the OPCN Delivery Framework “can be planned and developed to respect Indigenous peoples, languages, history, culture, knowledge and practices” with an emphasis on care coordination and seamless continuity across federal, provincial and community services.<sup>178</sup>

171 Charter of Relationship Principles for Nishnawbe Aski Nation Territory (July 24, 2017, online: <https://www.canada.ca/en/health-canada/corporate/transparency/health-agreements/charter-nan.html>) signed by Grand Chief Alvin Fiddler of Nishnawbe Aski Nation (NAN), then federal Minister of Health Dr. Jane Philpott, and Ontario’s then Minister of Health and Long-Term Care Dr. Eric Hoskins on July 24, 2017.

172 Nishnawbe Aski Nation, “Progress on NAN Health Transformation” (November 2018) at 2, online: <http://www.nan.on.ca/upload/documents/ht-progress-report-final-nov-8.pdf>.

173 Charter of Relationship Principles for Nishnawbe Aski Nation Territory (July 24, 2017), online: <https://www.canada.ca/en/health-canada/corporate/transparency/health-agreements/charter-nan.html>), at “The Vision” paras 5 and 6.

174 Charter of Relationship Principles for Nishnawbe Aski Nation Territory (July 24, 2017), online: <https://www.canada.ca/en/health-canada/corporate/transparency/health-agreements/charter-nan.html>), Guiding Principles 10, 11.

175 Ontario Palliative Care Network, *Palliative Care Health Services Delivery Framework: Recommendations for a Model of Care to Improve Palliative Care in Ontario* (April 2019), online: <https://www.ontariopalliativecarenetwork.ca/sites/opcn/files/OPCNHSDFRecommendations.pdf>) (OPCN 2019)

176 OPCN 2019 at 40.

177 OPCN 2019 at 41.

178 OPCN 2019 at 41-45.



- Launch of the First Nations Health Action Plan (2016).** In May 2015, the Chiefs of Ontario (COO) signed an accord to launch the plan with a focus on primary care, public health and health promotion, senior’s care, and life promotion and crisis support.<sup>179</sup> Ontario funded 16 primary care teams of which 15 were led by First Nations people. Access to traditional healers, nurse practitioners, and mental health practitioners that respect culture are weaved into these teams. Then Minister of Health and Long-term Care Dr. Eric Hoskins stated that they believe that a respectful partnership has grown, and the goal is to have these decisions be made in First Nations and managed by First Nations themselves.<sup>180</sup>
- Ontario’s Relationship with Indigenous Communities Guideline (2018).** The aim of this Guideline is inform the efforts of boards of health, municipalities, Local Health Integration Networks,<sup>181</sup> and other relevant stakeholders to reduce health inequities that persist for Indigenous communities, with an emphasis on “forming meaningful relationships with Indigenous communities that come from a place of trust, mutual respect, understanding, and reciprocity.”<sup>182</sup> Part of the *Relationship Guideline* emphasizes the importance of working closely with the federal government and First Nations communities to “develop models of integrating federal and provincial public health programs.”<sup>183</sup>

The LCO is aware that a wide array of community-specific, academic, professional, and other initiatives are additionally underway. Two of these projects are mentioned here:

- Six Nations Community-Based Palliative Care Program:** Developed and implemented a community-based palliative care program in Six Nations of the Grand River Territory, “grounded in a vision to provide access to quality palliative care at home and incorporate Haudenosaunee traditional teachings.”<sup>184</sup>
- Toronto’s First Indigenous Health Strategy 2016-2021:** This strategy was conceived by the Toronto Indigenous Health Advisory Circle to address the needs of the largest and most diverse urban Indigenous population in Ontario and to be led by community members themselves. Among the strategic goals are those directed at “harmonizing Indigenous and mainstream health programs and services” which includes implementation of Aboriginal portions of the Toronto Central LHIN Palliative Care Strategy, particularly in relation to culturally safe care; alignment with Indigenous midwifery practices; and implementation of family grief practices; and development of a live-in family healing and caring lodge.<sup>185</sup>

179 Ministry of Indigenous Affairs, “Political Accord Between First Nations and the Government of Ontario” (August 2015), online: <https://news.ontario.ca/mirr/en/2015/08/political-accord-between-first-nations-and-the-government-of-ontario.html>. This resulted in the Ministry of Health and Long-Term Care, “Ontario Launches \$222 Million First Nations Health Action Plan” (May 2016), online: <https://news.ontario.ca/mohltc/en/2016/05/ontario-launches-222-million-first-nations-health-action-plan.html>).

180 “Getting the Relationships Right: Health Governance in the Era of Reconciliation” Report of the First Nations Health Transformation Summit (February 2018), report of January 1 2019, online: <http://www.afn.ca/wp-content/uploads/2019/06/19-01-30-Health-Summit-Report-DRAFT-V4.pdf> ) at 2-3.

181 LHINs have since been repealed and are in the process of being replaced by Ontario Health Teams by virtue of the *People’s Health Care Act* (S.O. 2019, c. 5- Bill 74), online: <https://www.ontario.ca/laws/statute/s19005>.

182 Ontario Ministry of Health and Long-Term Care, “Relationship with Indigenous Communities Guideline, 2018” (January 2018) at 3, online: [http://health.gov.on.ca/en/pro/programs/publichealth/oph\\_standards/docs/protocols\\_guidelines/Relationship\\_with\\_Indigenous\\_Communities\\_Guideline\\_en.pdf](http://health.gov.on.ca/en/pro/programs/publichealth/oph_standards/docs/protocols_guidelines/Relationship_with_Indigenous_Communities_Guideline_en.pdf). (Relationship Guideline 2018)

183 Relationship Guideline 2018 at 19.

184 An article on the program is Verna Fruch, Lori Monture, Holly Prince, Mary Lou Kelley, “Coming Home to Die: Six Nations of the Grand River Territory Develops Community-Based Palliative Care” (International Journal of Indigenous Health, Volume 11, Issue 1, 2016 at 50), online: <https://journals.uvic.ca/index.php/ijih/article/view/15303>.

185 Toronto Indigenous Health Advisory Circle, *A Reclamation of Well Being: Visioning a Thriving and Healthy Urban Indigenous Community – Toronto’s first Indigenous Health Strategy, 2016 – 2021*, online: <https://www.toronto.ca/wp-content/uploads/2018/02/9457-tph-tihac-health-strategy-2016-2021.pdf>.

## D. Summary Conclusions about Current Law and Policy

The LCO's brief overview of recent federal and province legal and political developments suggest several forward-looking observations that will substantially influence Indigenous-led health law reform. This includes:

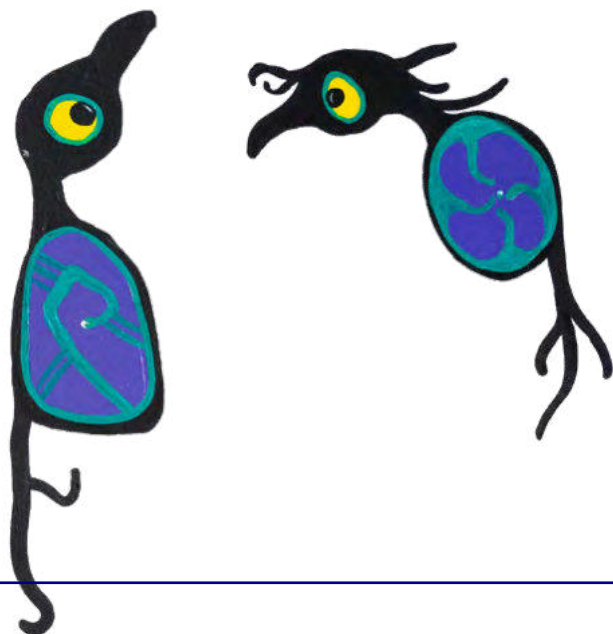
- **Acknowledgement that Indigenous-led, self-determined approaches to health will be fundamental to any future health law reform.**

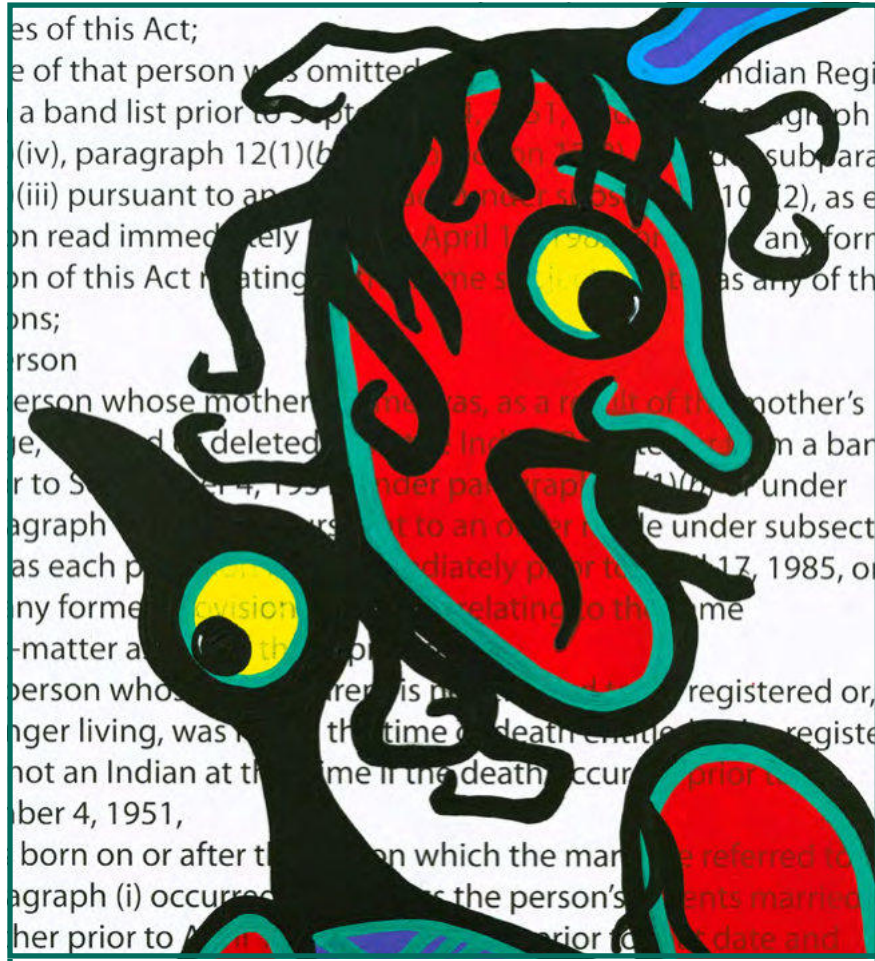
Enactment of UNDRIPA clarifies that self-determined Indigenous beliefs, values, practices, ceremonies and law will be at the center of future law reform discussions.

- **Jurisdictional issues will be complex.** The complex quilt of existing health care rights, laws and services, along with the need for common understanding around a wide array of health issues, will make the law reform complicated. Approaching discussions “with a blank piece of paper and a mandate that the tables are co-developed between negotiators for both sides” invites consideration of legal subject matters, such as health, as part of the “full box” of rights. This may carry sweeping implications for closely interconnected health rights which involves complex questions of provincial, federal and territorial jurisdiction; funding arrangements; and a wide array of closely intersecting laws including professional regulation, health care consent and capacity, guardianship, workplace safety, and so on.

- **Indigenous-led law reform will probably require support.** While not an exhaustive list, this is likely to require the support of at least the following:

- Additional administrative, financial, and other support for indigenous communities, including urban communities to fully participate as equal symmetrical parties in the process of co-creation. It will require considerable effort and some legal expertise to conduct preparatory surveys of subject matters and priorities derived from traditional Indigenous cultural, social and legal structures, identify the specific points in law where these distinctions intersect, and then (re)define these or new distinct laws for negotiation. Indigenous communities will likely need additional resources and support to undertake such efforts.
- Judicial, adjudicative, and administrative flexibility as issues are identified and new approach are taken, many of which may go to foundational jurisdictional mandates. As greater self-determination in services and programs is facilitated, expectations will change and this will likely result in the acceleration of novel applications to courts and tribunals that oversee the health care system with issues like professional misconduct, health service eligibility, disputes arising from health care consent and guardianship laws, and human rights discrimination and accommodation in health care facilities and services. Greater familiarity with indigenous law and approaches to co-creating the law will likely be required





## 4 Promising Directions for Future Law Reform

This report does not repeat the analysis or recommendations in the LCO’s *Last Stages of Life: Final Report*. That *Final Report* assessed 13 major issues and made over 50 recommendations to laws and policies affecting the last stages of life, including:

- Advance care planning and health care consent;
- Expanded Palliative Care Public Health promotion;
- Resolving health care related disputes;
- Better workplace wellness supports for health care practitioners;
- Better employment supports for caregivers; and
- Improved supports for vulnerable communities with unmet needs.

This report addresses Indigenous last stages of life. Our focus in this report is the experiences, concerns, traditional laws, practices, and cultures of Indigenous people in Ontario. In contrast to the *Last Stages of Life: Final Report*, this report does not include specific law reform recommendations. This report rather identifies “promising directions” for further discussion between the government and Indigenous communities in these matters.

## A. The Disparity between Indigenous Views and Health Care Terminology and Law

A key recommendation of the LCO’s *Last Stages of Life: Final Report* details the need for greater consistency in how “palliative” is defined in Ontario health law and policy.<sup>186</sup>

Legally, the term appears in Ontario’s *Health Care Consent Act* as an example of “treatment” but is not defined in any greater detail. As a result, various regional and even local definitions and criteria are used to determine access to “palliative” services, including for major needs like home care or priority admission to long-term care. The lack of a consistent definition of “palliative” creates confusion elsewhere in the law too. For instance, employment leave protections may not align with health care programs, and labour laws may not acknowledge palliative care as a high-stress work environment.<sup>187</sup> Unsurprisingly, the ambiguity in defining “palliative” has resulted in litigation, most notably before the Supreme Court of Canada case in *Rasouli*.<sup>188</sup>

Alongside legal developments the public’s understanding of “palliative care” is also rapidly shifting. At one time, palliative care was generally understood as just the last few days or weeks of life, often in acute care hospitals or hospices. More recently, palliative care is increasingly understood as a continuum of care and a philosophy or program of patient support that may take place over months or years, and which also includes a clinical component available in acute, long-term, and home or community settings.

These issues are discussed in detail in the LCO’s *Last Stages of Life: Final Report* and the preceding *Discussion Paper*.<sup>189</sup>

Through engagement with Indigenous communities, the LCO heard that the prevailing Western conceptions or definitions of “palliative care” – old or new – can have a dramatic affect of Indigenous culture, practice, traditions, law and beliefs in some of the most critical and profoundly spiritual stages in the life of an

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186 LCO LSL Final Report 2021 at Recommendation 1 p. 25-27.

187 LCO LSL Final Report 2021 at Recommendation 1 p. 25-27.

188 *Cuthbertson v. Rasouli* ([2013] 3 SCR 341). This case in part revealed how closely connected palliative and other forms of social care are in sensitive debates occurring on the right to decide whether a person will receive life-saving or life-sustaining treatments, such as feeding tubes and artificial ventilation, particularly where there is little chance of improvement in the patient and interventions may be seen as medically futile. Insofar as beliefs and practices surrounding the dying process can be quite different across faith, culture, age, gender and other equality-seeking groups, Ontario’s system will be called upon to proffer an array of services that enable individuals and communities to exercise nuanced choices.

189 A fuller discussion of these views is available in the LSL Discussion Paper 2017 at Chapter 2.B, “B. Recent Debates about Rights Nearing the End of Life”

individual and their community. The prevailing use of “palliative care” as a medical intervention removes end of life care from Indigenous communities. This significantly undermines Article 24 of UNDRIP which emphasizes the obligation to recognize Indigenous conceptions of wellness. Article 24 affirms that Indigenous persons have “the right to their traditional medicines and to maintain their health practices, including the conservation of their vital medicinal plants, animals and minerals.”<sup>190</sup>

Indeed, the need to align palliative care from an Indigenous perspective is believed to be fundamental:

*First Nation communities hold an enormous amount of traditional and community-based knowledge and expertise in negotiating the personal, familial and community experiences of caring for community members who are sick. However, through colonization, health systems have been imposed on First Nations peoples which typically do not support Indigenous approaches to care.*<sup>191</sup>

*Historically, many palliative models of care have highlighted the challenges First Nations, Inuit, Métis, and urban Indigenous patients and their families/caregivers face, drawing attention away from recognizing and building local knowledge and community capacity. These challenges include... lack of trust in mainstream providers and providers’ lack of understanding of Indigenous cultural beliefs, values and practices.*<sup>192</sup>

For some Indigenous traditions, the language of palliative care contradicts worldviews and makes it difficult to understand that palliative care is meant to improve quality of life with no emphasis on dying. The term “palliative care” is not used and teachings are about “passing” into the spirit world and the strong importance of dying at home surrounded by community. In this view, end of life is a “healing process” and dying is an experience of family, community, and spirituality.<sup>193</sup>

The “palliative” period may also coincide with traditional approaches to preparing for death that can be quite extensive. One example of this approach and its inherent plurality is found in *The Journey Back Home*, published by Six Nations Long-term Home & Community Care Program.<sup>194</sup> Over 44 pages it shares:

- Legends, stories and teachings about dying and death;
- Ceremonies and traditional medicines and practices to calm and comfort the dying person;
- Preparing for the journey with an Indian name and a personal song; beliefs on turning off life support equipment, and;
- Procedures distinguishing between different kinds of death (for example traumatic (murder), natural (old age), suicide, accident, illness/disease, miscarriage).<sup>195</sup>

After death the document describes procedures for body preparation; ceremonial clothing to be worn, and how the wake and funeral are to be held; what the mourning period is and when ceremonies and feasts should occur; and shares variations in how different Haudenosaunee communities – including the Onondaga, Cayuga, Seneca, Sour Springs, and Mohawk – arrange their longhouses and funeral seating.

190 UNDRIP Article 24.

191 EOLFN Palliative Workbook 2015, supporting the development of palliative care programs in First Nations communities, at 6.

192 OPCN 2019 at 17.

193 EOLFN Palliative Workbook 2015.

194 Six Nations of the Grand River Territory Long-Term Care Home and Community Care Program, *For the Ones Left Behind: Coping with Grief and Loss through Traditional Ways* (Ohsweken, Ontario: 2011). See also the updated and expanded version, Six Nations of the Grand River Territory Long-Term Care Home and Community Care Program, *The Journey Back Home* (Ohsweken, Ontario: 2018).

195 Journey Back Home at 5-8.

Importantly, it is meant to be read as a living document that “may have different variations of correctness.”<sup>196</sup> It is complimented by other references, such as *Little Flower’s Sad Time*, a story that explores the process of explaining death to a child.<sup>197</sup>

The stigmatizing effects of language, and the role of the law in promoting that stigma, was specifically considered at a symposium in 2016 exploring palliative and end-of-life care for First Nations, Inuit and Métis people. There delegates discussed how:

*... the negative stigma attached to palliative care prevents Indigenous and non-Indigenous patients from seeking early care... Participants spoke of the difficulty in relaying the information that palliative care was about improving the quality of life while living with serious illness. Other concerns included the current language of palliative care, which is in contradiction to Indigenous worldviews. Speakers of different tribal affiliations mentioned that often there is no word for death and dying in their languages. Incorporating culturally safe practices requires understanding that these different ways of knowing exist.*<sup>198</sup>

Strategies to counteract such fears were discussed and included “changing technical and palliative care language, using story-telling to gain buy-in, and grounding educational resources in Indigenous customs and beliefs.”<sup>199</sup> TRC Calls to Action 13 and 14 highlight another important potential recommendation, namely, by mandating the presence of language translators who can use culturally relevant and appropriate words and “Adapt the current language of palliative care to be grounded in Indigenous customs, beliefs, and traditions to reduce the stigma associated with palliative care.”<sup>200</sup>

“Palliative” is further laden with intersecting statutory meanings that play an important role in end-of-life care. For example, “best interests” decision making<sup>201</sup> and health care “standards of practice”<sup>202</sup> are frequently defined and evaluated within the available range and prognosis of Western medical interventions. In the often rushed and pressured give-and-take of daily interactions, these assumptions can become the default norm that displace or entirely marginalize Indigenous traditions, practices, culture and laws, not to mention traditional medicines and foods. It can also render Indigenous patients as akin to a “cultural group” in Canada rather than the unique and distinct constitutionally recognized people they are. Cases which have challenged this demonstrate how and why we need thoughtful conversation on the matter, not litigation.<sup>203</sup>

196 Journey Back Home at 2.

197 Brenda Sandy, *Little Flower’s Sad Time*, MTS Native Services, Six Nations of the Grand River, 2016).

198 GIPPEC Symposium Report 2016 at 25.

199 GIPPEC Symposium Report 2016 at 25.

200 GIPPEC Symposium Report 2016 at 33, 35. TRC Calls to Action 13, 14.

201 HCCA s. 21(2); s. 37(1).

202 *Regulated Health Professions Act, 1991* (S.O. 1991, c. 18). The medical “standard of practice” includes all the professional, legal and ethical aspects of medical practice that have been clarified by statute, case law and the policies of provincial medical regulatory colleges. For an expanded discussion of “standards of practice” and of proposed “standards of care” in the palliative and end-of-life context, see James Downar, Laura Hawryluck, et al., “Balancing The Interests Of Patients, Substitute Decision-Makers, Family And Health Care Providers In Decision-Making Over The Withdrawal And Withholding Of Life-Sustaining Treatment” (Law Commission of Ontario Commissioned Papers series, April 2017, online: <https://www.lco-cdo.org/wp-content/uploads/2015/05/Downar-et-al.-Final.pdf>).

203 In the health care context particularly, consider *Hamilton Health Sciences Corp v D.H* (2014 ONCJ 603) and as amended in (2015 ONCJ 229), discussed above.

Prevailing Western conceptions of palliative care are also implicated in defining operational and policy terms that result in the routine exclusion of traditional Indigenous laws and practices. Supports, services, and other legislative frameworks only become available according to the Western conception and not the local Indigenous conception. Needless to say, much of this is made more difficult in a formal and highly regulated setting like a hospital, or in a network of acute, home care, and specialist health care services.

As one person put it:

*There is concern about what the terms “palliative” or “end of life” mean in an Indigenous community. These compel certain assumptions and directions. Other communities are now asking [me] how they can build capacity, how they can connect with Indigenous practices. They’re following the Lakehead [EOLFN Project] report and getting interested and wanting to do this.<sup>204</sup>*

One community expressed further concern that “palliative” is an unfamiliar term to many community members, who often experience the regulation of people upon birth and death as linked to colonialism. The LCO heard many calls for flexibility in allowing the community to make these decisions themselves.<sup>205</sup> But to achieve such self-determined services involves what were identified as a series of workarounds. These were characterized as attempts at succeeding *despite* existing legal and regulatory frameworks rather than because of them:

*We only succeed despite the legislation, not because of it.<sup>206</sup>*

*The Ministry of Health thinks palliative care is “a year.” But for us it might be a lot longer than a year. They think of it as a linear trajectory. A lot of this is based on census data. And planning is based on the census – but [First Nations Community] didn’t participate in the census so we’re a black hole.<sup>207</sup>*

*When we try to meet funding requirements it’s doing things that aren’t what our community needs are, so we still try to make what our community needs. We are massaging the funding agreement to try and get what we need in the way we need it.<sup>208</sup>*

The prevailing Western conception of “palliative” is also laden with basic assumptions of the characteristics of the population. Again, in the Indigenous context, these can be misleading, harmful, and exclusionary. Many of those we spoke to highlighted how service eligibility and priority are given to those on the basis of an apparently neutral characteristic, such as advanced age, but which may have an indirect discriminatory effect on Indigenous health seeking populations:

*Our age of death is 20 years below the Canadian norm, like the prison population. So demographic planning is one thing but the reality is our population has more and higher complex needs earlier and longer. So the definition of “palliative” is colonial.<sup>209</sup>*

204 LCO Engagement notes, community health program worker.

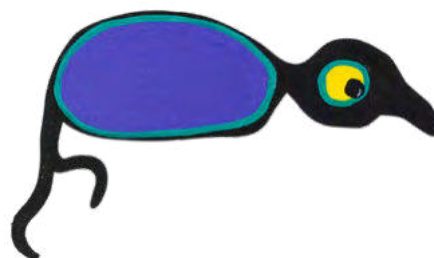
205 LCO Engagement notes, Indigenous health care centre staff.

206 LCO Engagement notes, Indigenous health care centre staff.

207 LCO Engagement notes, Indigenous health care centre staff.

208 LCO Engagement notes, Indigenous health care centre administrator.

209 LCO Engagement notes, Indigenous health care centre staff.



*If our people are dying younger, what traditionally constitutes the long-term care patient? The admission criteria don't match the population who might have early onset illnesses yet don't qualify for LTC. We see people age 40-50, 4 stage kidney disease, does that qualify for LTC?<sup>210</sup>*

*I never hear anything from the LHIN about supporting Indigenous clients. They're pretty good about knowing what projects are going but we aren't hearing anything. The LHIN is so square, its very black and white. It's not about looking at the person in their environment, it's about if you're at end of life you get this.<sup>211</sup>*

There are promising alternatives. For example, the Akwesasne community is planning to implement a Palliative Performance Assessment Scale. This assessment would help educate families about palliative care as a healing practice where the emphasis is on respecting traditional community care practices:

*Natural laws / traditions / ceremonies come first, including when someone passes away, that's what guides an end-of-life process, if that is the correct term... Traditional medicine program comes first, and informs all work of Health Department.<sup>212</sup>*

Other experiences have been positive in allowing local definitions to flourish. As noted by the OPCN:

*There are many successful local models of care grounded in community strengths that outline how palliative care services can be delivered safely to support and respect Indigenous peoples, languages, history, culture, knowledge and practices.*

*Successful models use a trusting, participatory, and culturally safe approach, involve collaborative interdisciplinary palliative care teams of conventional culturally competent providers, as well as Indigenous providers. They have formalized jurisdictional collaborations across organizations and all level of governments and engage in seamless care coordination and management.*

*Through these models, First Nations, Inuit, Métis, and urban Indigenous patients have experienced the comfort of dying at home with support from their families, culture, and ancestral land, better medication adherence, improved symptom management and quality of life. Furthermore, they have also reported high satisfaction with emotional, practical, and spiritual support, and greater willingness to engage in advance care planning. There were also provider and system level benefits that include provider satisfaction, reduction in total healthcare costs, hospitalizations, and ED visits.<sup>213</sup>*

210 LCO Engagement notes, Indigenous health care centre staff.

211 LCO Engagement notes, hospice social worker.

212 LCO Engagement notes, Indigenous health care centre staff.

213 OPCN 2019 at 41.



This model of local definition and delivery stands in stark contrast with recent efforts at outreach from the Ontario government to Indigenous communities, such as the Chiefs of Ontario rejecting an “advisory” role for Indigenous people under Ontario’s new *The People’s Health Care Act, 2019*.

Many participants proposed approaches that would return power to Indigenous communities and give them a greater and more active sovereign role in co-creating existing and future legislation:

*I’ve been thinking about it and comparing it to the French Language Services Act as something all other legislation has to take into account and comply with. There is no “Indigenous Services Act” like that and we don’t have a mechanism like that, but in the Indigenous community we’ve been working on it. There hasn’t been any change unfortunately. The FLSA is a good reference point, and there was supposed to be a parallel Act for Indigenous communities.<sup>214</sup>*

*If you’re not a health care provider, and you identify [someone’s] need for more provider care, there is only the hospital to refer to. You can’t have your issue addressed by the LHIN practically or systemically. Instead we need to create Indigenous entities, like under the French Language Services Act. They have staff, they have regulation and powers, but we never got that. We just got aboriginal volunteers from the LIHN. They have no legal mechanisms to support their work or influence.<sup>215</sup>*

*Other people in Canada have rights to language, religion, and culture. But these are the things legislated under the Indian Act for us to lose: traditional practices, language, and culture. French people in Ontario also have access to services and education in French – but for Indigenous communities there’s legislation that takes those rights away from us.<sup>216</sup>*

Developing distinct approaches to palliative and end-of-life care are also themes which are strongly echoed in both the OFIFC response to the federal *Framework on Palliative Care in Canada* and the OPCN’s *Delivery Framework*, the later of which recommends that:

*First Nation, Inuit, Métis or urban Indigenous patient and their family/caregivers will receive palliative care that utilizes grassroots, participatory and collaborative approach and incorporates cultural knowledge into all aspects of care.<sup>217</sup>*

All that considered, the role of law in shaping exclusionary experiences does not necessarily mean a solution to these problems is also within the law, or at least the state-centric version of it. Several of those engaged with us had hesitation with the idea of addressing these issues through Ontario and Canadian law because it removes power from the community:

*Think as always that this isn’t an exception; it’s a totally different value system. There is a need to minimize the risk of dampening creativity or co-opting or that there might be a punitive ramification from that by situating solutions in the law.<sup>218</sup>*

214 LCO Engagement notes, Indigenous health care centre staff.

215 LCO Engagement notes, expert in Indigenous health policy.

216 LCO Engagement notes, expert in Indigenous health policy.

217 OPCN 2019 at 41.

218 LCO Engagement notes, Indigenous community member with legal expertise.

*There's also a real risk in looking at Ontario and Canadian legal system to solve problems. Examples: how law has defined "Indigenous midwives" but they pay them less; or the idea of an "Indigenous hospice" and how that could be minimized; or if you were to carve out a space and allow for a definition of "Indigenous palliative care" in the HCCA it could be used to minimize the supports or services.<sup>219</sup>*

Acknowledging that a legislated term like "palliative" is laden with an intersecting network of colonial legal assumptions is only the first step towards any potential range of legal solutions to it. Recognizing the distinctiveness and self-determination of Indigenous "palliative" health care may instead require approaches like the recent effort in British Columbia to legislate alignment of all provincial law with UNDRIP.<sup>220</sup> As discussed earlier, this would create space to honor provisions like UNDRIP Article 24 and ensure that health care law, regulations, services and operational program and policies are defined by self-determined Indigenous conceptions of supporting community members in the last stages of life. This could also be enacted through the use of more local framework agreements that begin with the recognition of both state and Indigenous self-determination and sovereignty. Recent example of this approach can be found in the *Kunst'aa Guu – Kunst'aayah Reconciliation Protocol*, or the Nishnawbe Aski Nation's *Charter of Relationship Principles Governing Health System Transformation in NAN Territory*.<sup>221</sup>



219 LCO Engagement notes, Indigenous community member with legal expertise.

220 BC Bill 41. See also end note 35.

221 See: *Kunst'aa Guu – Kunst'aayah Reconciliation Protocol* Between the Haida Nation and Her Majesty the Queen in Right of the Province of British Columbia (2009), online: [http://www.haidanation.ca/wp-content/uploads/2017/03/Kunsta-guu\\_Kunstaayah\\_Agreement.pdf](http://www.haidanation.ca/wp-content/uploads/2017/03/Kunsta-guu_Kunstaayah_Agreement.pdf). See also Nishnawbe Aski Nation's *Charter of Relationship Principles Governing Health System Transformation in NAN Territory* (July 24, 2017), online: <https://www.canada.ca/en/health-canada/corporate/transparency/health-agreements/charter-nan.html>.

## Promising Directions for Future Law Reform

1. Indigenous communities should be engaged with both provincial and federal governments in defining supports in the later stages of life that are distinct from inherited terms like “palliative” and in which Indigenous services, programs and other practices are defined, organized and governed by traditional laws, culture and practices.
  2. Provincial health care and intersecting legislation should be reviewed and made consistent with commitments required under UNDRIP and the TRC *Calls to Action* to ensure equitable and culturally safe access to health care everywhere in the province.
  3. Look to Indigenous-led initiatives for guidance on recovering and prioritizing Indigenous traditions, laws, practices, culture and experiences in relation to palliative care, such as the OPCN’s Delivery Framework section on Palliative Care for First Nation, Inuit, Métis and urban Indigenous Communities and the Lakehead Improving End-of-Life Care in First Nations Communities.
  4. Being open to the development of new performance measures, funding arrangements, OHIP billing codes, and recognition of traditional medicine, practices and knowledge in order to satisfy the needs of self-determined and self-defined programs and services.
- Steps that the province of Ontario could take to further these goals:
- Consider the establishment of an *Indigenous Language Service Act*, akin to the *French Languages Services Act*, or the legislated commitment by the province of British Columbia to make all legislation comport with international Indigenous legislation. Among other things, this would better ensure culturally relevant translation services in the province, and foster the expertise needed to engage in culturally relevant review of provincial legislation for such terms as “palliative.”
  - Create space for Indigenous communities to develop their own definition of terms like “palliative” through multi-jurisdictional health partnerships with these communities and greater self-determination in defining services, programs and health practices.
  - Foster the development of a working group made up of front-line Indigenous health service providers to identify and audit areas in OHIP billing and funding codes that could be improved through a culturally competent lens.



## B. Acknowledging Institutional Racism, Discrimination and Barriers to Cultural and Spiritual Practices

The introduction to this report (Section 2) makes several observations on the reality of anti-Indigenous racism endemic to health care in Canada. The introduction reviewed Canada's commitments to ensure equitable access to health care that is free of discrimination. This includes commitments made under the Truth and Reconciliation Commission *Calls to Action*, and under UNDRIP.

We further noted how other provinces are beginning to confront anti-Indigenous racism within their own jurisdiction.

British Columbia commissioned a landmark report which confirmed how widespread Indigenous-specific stereotyping, racism and discrimination limits access to medical treatment and primary and preventative health care. This disproportionately impacts women and girls and creates a reliance on emergency services and hospitalization for avoidable reasons, with poorer health outcomes.<sup>222</sup>

Quebec has publicly apologized and admitted to “failing in its duty” to Joyce Echaquan, who died shortly after filming staff insulting her in a video she shared on Facebook live.<sup>223</sup> Her death was subsequently investigated through a coroner's inquiry in 2021 and which confirmed that “The racism and prejudice that Mrs. Echaquan faced was certainly a contributing factor to her death.”<sup>224</sup>

Ontario is similarly obliged to confront these realities. The Ontario Palliative Care Network's *Delivery Framework* report describes how systemic discrimination is impacting health care outcomes in Ontario, and specifically in the last stages of life:

*These collective histories have significantly impacted the planning, quality, access, continuity, appropriateness, and delivery of palliative care. Moreover, as a result of residential schools, systemic discrimination, and fear of institutionalization, many First Nations, Inuit, Métis, and urban Indigenous patients and their family/caregivers experience unresolved and intergenerational trauma, suppressed Indigenous identity, and disruptions that include language, cultural healing practices, social networks and connection to lands. These traumatic experiences have led to compromised care.*<sup>225</sup>

These observations are reflected in other studies conducted in Ontario, notably the Wellesley Institute's report *First Peoples, Second Class Treatment*.<sup>226</sup> The report confirms how racism in Canada's health care system is so prevalent that it manifests as a social determinant of health for Indigenous communities and patients. Consequently, Indigenous people experience the worst health outcomes of any population group in Canada.<sup>227</sup>

222 The Independent Investigation into Indigenous-specific Discrimination in B.C. Health Care, *In Plain Sight: Addressing Indigenous-specific Racism and Discrimination in BC Health Care* (November 2020), online: <https://engage.gov.bc.ca/addressingracism/>, at 21, 25, 29, 33-35.

223 CBC News, “In apology to Joyce Echaquan's family, Quebec premier says public service ‘failed in its duty’” (October 6, 2020), online: <https://www.cbc.ca/news/canada/montreal/joyce-echaquan-funeral-1.5752176>.

224 See Coroner of Quebec, *Investigation Report Concerning the Death of Joyce Echaquan* (September 8, 2021) at page 20, online: [https://www.coroner.gouv.qc.ca/fileadmin/Enquetes\\_publicques/2020-06375-40\\_002\\_1\\_sans\\_logo\\_anglais.pdf](https://www.coroner.gouv.qc.ca/fileadmin/Enquetes_publicques/2020-06375-40_002_1_sans_logo_anglais.pdf).

225 OPCN 2019 at 40.

226 Wellesley Institute, *First Peoples, Second Class Treatment: The Role of Racism in the Health and Well-Being of Indigenous Peoples in Canada* (2015) at 2, 8-10, online: <https://www.wellesleyinstitute.com/publications/first-peoples-second-class-treatment/> (Wellesley 2015).

227 Wellesley 2015 at 9.

There is also a growing body of research in the US and Australia identifying racism as a chronic stressor implicated in the health of African Americans and Indigenous Australians.<sup>228</sup> A 2012 study examining experiences of racism among Aboriginal university students in Edmonton, Alberta found that student reactions to racism were indicative of “racial battle fatigue” described as the depletion of mental and physical resources due to the constant engagement of stress response systems to cope with ongoing discrimination.<sup>229</sup> Disparities that can not be explained by socioeconomic status alone instead point to the “wear and tear of experiences of racism and discrimination in regular encounters with societal institutions and in everyday life.”<sup>230</sup>

The LCO heard many of these concerns from those we spoke with from across the province. Their comments create a mosaic of what is happening and how it irrevocably impacts health care.

*The health care system funded a study in Thunder Bay, a survey of 200 Indigenous adults and 50 children. A companion study in other communities is also a third of the way through surveying a further 600 adults. But already, what we’re hearing, is that the number one concern is racism.*<sup>231</sup>

*One Elder is in retirement home stripped herself of her regalia because she doesn’t want anyone to know she is Indigenous. She gets dressed elsewhere, and she does the reverse going back, if she doesn’t feel safe, what happens when they end up in ward that they’re scared to speak of their identity. There is racism, stigma, and isolation. That is where they should feel comfortable, and they don’t.*<sup>232</sup>

*Because of all these awful health care experiences we do not seek help or follow up on medical issues. That longstanding relationship impacts our mortality.*<sup>233</sup>

*Both the Indigenous individuals who died in my care had significant substance use issues and that became a barrier itself.. I spent a lot of time with a patient in ICU telling her story to the staff, and one of the docs came and thanked me for telling it. As soon as I was the one telling the story the approach of the care team shifted. The patient had a history of abuse so when the care team held her arm down to inject something she freaked out. So this links to inter generational Indigenous trauma too.*<sup>234</sup>

Fundamental to addressing this is an understanding that colonial regimes do not just impose law and policy: they disrupt and displace what was pre-existing. The aim is not just to recover these pre-contact values and practices but to re-assert the traditional autonomy and self-determination they represent.

228 Wellesley 2015 at 9.

229 Wellesley 2015 at 9.

230 Wellesley 2015 at 9.

231 LCO Engagement notes, Indigenous health care centre staff.

232 LCO Engagement notes, Indigenous health care centre staff.

233 LCO Engagement notes, Indigenous community member.

234 LCO Engagement notes, nurse providing care in community hospice.

This sentiment was shared by those the LCO engaged with. Many expressed a commonly and strongly held view that existing systemic protections against racism and institutional discrimination are not having a broad and meaningful impact. This includes a full range of existing instruments, for example:

- Legislation, standards and redress mechanisms described under the *Human Rights Code*;
- Workplace equity initiatives;
- Attempts to make health care program and service eligibility and practice policies more accommodating;
- Increased Indigenous participation in partnership, advisory, and management roles;
- Dispute resolution mechanisms to professional regulatory bodies;
- Complaints mechanisms within health care institutions.

The LCO heard consistently that when issues were raised, existing systems of redress were found ineffective:

*I sit on the Consent and Capacity Board, it's going to be ten years. And in that time I've only seen three Indigenous applicants. They're so afraid to challenge the system, they're so afraid to say I don't agree. That bothers me...<sup>235</sup>*

*A nurse at a [mid-sized city] hospital made a blatantly racist comment with a woman who was coming into deliver her baby, but no one has reported her to the College. Racism is not seen by others as a breach in the standard of care.<sup>236</sup>*

*Our local hospitals aren't great. There is lots of stereotyping especially when people are using substances, homeless, or have mental illness. I've had three Indigenous clients I've walked through to the end of life and it was rough. One was living at [a shelter] and went to hospital. They wouldn't allow smudging because he was in ICU. The community was around him but they'd only allow one person in at a time. As a professional and white woman you want to advocate but they're not listening.<sup>237</sup>*

*There's one nurse who when she feels people aren't being listened will ask if they feel like they're being silenced. And if so she will take it up the chain. But a lot of people don't have someone to do that. And if that person isn't there or has a day off it's precarious. This needs to be better supported and formalized.<sup>238</sup>*

*We had a patient, it was critical and they needed hospital, but this patient has experienced racism at the local hospital. The hospital had refused to let them take an ambulance even though it was critical. They wanted us to be in cab to send him to [the next city over]. They should have died. But they chose to take a cab, away from families from support to come to another city for service.<sup>239</sup>*



235 LCO Engagement notes, Indigenous health care centre staff.

236 LCO Engagement notes, Indigenous health care centre staff.

237 LCO Engagement notes, nurse providing care in community hospice.

238 LCO Engagement notes, nurse providing care in community hospice.

239 LCO Engagement notes, Indigenous health care centre staff.

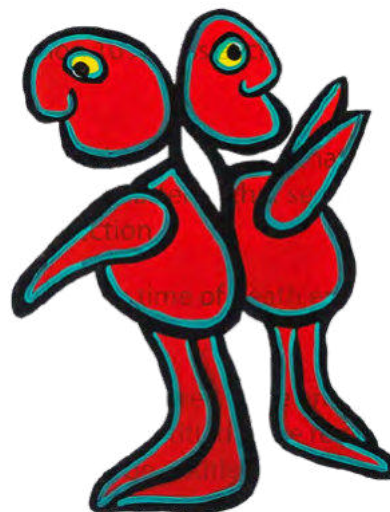
*When issues do arise there is an ethics and investigation but we have no levers to accountability or flowback from one or many occurrence. We work with a hospital and it gets investigated but nothing happens. The ongoing lived experience is bad. There's no feedback loops back to us about what happened or how it was resolved.<sup>240</sup>*

*The regional ethicist also gets resistance. And she's even a physician! The greater problem is that the patient experiences are not flowing back to get resolved. If something gets triggered out of a bad experience in the previous care pathway they are retraumatized. Are our people even willing to access complaints resolution mechanisms? The complaints system is seen as Western. It's there to protect the hospital. [Our community] health services are undertaking to engage with the [local hospital] to create a hospital advisory council to create a forum with the hospital. It would allow the local patients and community members to complain locally and then bring those issues to the hospital through our own professionals. But this takes away from the work we do every day; we have to volunteer all our time; and you have to spend all the time educating the person who is supposed to be your advocate in the institution.<sup>241</sup>*

The LCO also heard many responses outside of existing institutions desiring to re-assert traditional autonomy and self-determination over health care. It was commonly felt that meaningful improvements would best be achieved by creating Indigenous specific services, staffed by Indigenous people, and overseen by Indigenous people in management roles. Such self-defined services would pre-empt the uneven distribution of health funding, resources, and services according to state-constructed Indigenous identities.<sup>242</sup>

*What is there for services that is Indigenous specific? Nothing. So many people are feeling vulnerable, lived a life where people have been racist to you, feeling extremely vulnerable, you're not feeling most combative, or empowered. They go back to their mother tongue, if you're in a place with no Indigenous serving you you're going to feel out of place.<sup>243</sup>*

*Based on conversation we've had, one interesting thing that keeps coming up is the need for independence. Places are struggling to maintain independence and it's really difficult. Partners don't have any Indigenous people in leadership, partners are unacknowledged. But some places are slowly starting to evolve, a big part of what they do, to and for Indigenous patients and clients, is where I hear more optimism in creating their own programs and policies. It's all a work around.<sup>244</sup>*



240 LCO Engagement notes, Indigenous health care centre staff.

241 LCO Engagement notes, Indigenous health care centre staff.

242 Wellesley 2015 at 9.

243 LCO Engagement notes, Indigenous health care centre staff.

244 LCO Engagement notes, Indigenous health care centre staff.

These challenges are also manifest for Indigenous health care practitioner. Several practitioners in different roles spoke candidly about how their professional education and experiences minimize their identity as an Indigenous person:

*The medical field obliterates the “self”, such that Indigenous medical staff subordinate their identity to medical teachings and practices, which conflicts with conceptions of culturally appropriate care.<sup>245</sup>*

*Professional regulators don’t acknowledge Indigenous autonomy. They are governance structures for professionals, and MAY have some Indigenous projects, but its not distinct. Professional practice standards ask for “respect” and “culturally sensitive care” but this doesn’t really address the needs of Indigenous needs, the relationships that need to be developed, or addressing systemic racism perpetrated by the health professionals. So [name] is leading a small subcommittee of [volunteers working with the federal association of a regulated health professional group] to try. Some of what they’re trying to address are the structural issues. The College should set the standards for how we practice but most of the regulatory issues are around billing, misrepresentation, etc. She’s never seen anyone reported for racism. It’s also an enforcement and accountability issue within the existing structures and opportunities they have in existing regs, standards, and guidelines. But they’re not being reported.<sup>246</sup>*

*Our hospice has done a bunch of cultural competency training. I just did two sessions with [name] who does harm reduction work and with Indigenous perspectives on harm reduction. Packed room. Hospitals aren’t doing any of this and they should be. Should be part of baseline professional training. Need to take time. Listen to stories. And the results are no need to use restraints. My number one recommendation is that there should be education in medical school on all this and basic human rights.”<sup>247</sup>*

The LCO heard other ways that institutions can improve:

*The hospital was demanding that patients give them a band number in order to get service, but there’s no purpose in having band number, it’s just discriminatory and labeling. But there’s some new management so we’re hoping things will start to change. They’re very resistant in the hospital. Even if we wanted to smudge, it was a whole protocol, no one smudges there but they’re starting now.<sup>248</sup>*

*We have 12 harm reduction centres in [this community], it’s a good money maker for units and for pharmaceuticals. Many pharmacies come to speak to us and want to set up shop inside our aboriginal health centre. Every time we spoke to them we say our philosophy is to ween people off pharmaceuticals because of the harm they cause. They have no incentive to stop; they can bill for the prescription, making someone better transition from opiate, to methadone, no incentive to transition them to nothing. You see people line-up for it every day.<sup>249</sup>*

245 LCO Engagement notes, Indigenous physician.

246 LCO Engagement notes, hospice social worker.

247 LCO Engagement notes, nurse providing care in community hospice.

248 LCO Engagement notes, Indigenous health care centre staff.

249 LCO Engagement notes, Indigenous health care centre staff.



The LCO heard many examples of how traditional spiritual and cultural practices are routinely discriminated against in institutional policies, including smoking, cedar baths, pipe ceremonies, traditional medicine, food, and other health practices. WE also heard many examples of how institutions were unwilling to accommodate these practices:

*Folks who chose to use traditional medicine only for their illness, but still want monitoring. They're being told no to the monitoring, i.e., if you don't want chemo we won't give you the CT scans.<sup>250</sup>*

*We do a lot of local palliative care with local traditional medicine but they are overworked too. The Western order doesn't recognize the traditional medical healers.<sup>251</sup>*

*I took a bundle into the hospital and opened it right a up. I saw how they looked at me. It looks like junk to you but there is a story for every piece. Whether I'm carrying that piece alone or all of it together you don't have right to throw it out, it's part of my medicine.<sup>252</sup>*

*We asked the CEO and CCO at the hospital who takes the cultural competence training? Answer was that it's not mandatory. It should be mandatory. Everyone has to do it. It's a check box approach to understanding what local Indigenous issues are. And it needs to be tailored to the local community.<sup>253</sup>*

*Colonization has resulted in the health crisis, particularly manifest in mental health these days. Our cultural foundation can help bring us to a healthy state again. But it's a really small group of people who need to help inform all of our health services. How do we draw on people we know to help build into a health promotion programs, our food, etc. We have all this healthcare money but a lot of the resources to develop a sensible Indigenous health care system aren't there, to incorporate traditional medicines and services. That's not funded."<sup>254</sup>*

The LCO heard that Indigenous people, communities and organizations have to constantly fight institutions to recognize their spiritual and cultural practices. We heard many times how exhausting these fights can be, and the burden it places on individuals, families and communities.

As a law reform organization with human rights experience, this situations raises significant questions about how to ensure the Ontario **Human Rights Code** is given life, particularly in “soft law” instruments like facility policies and practices, LHIN service accountability agreements, safety regulations, and other such instruments.



250 LCO Engagement notes, Indigenous health care centre staff.

251 LCO Engagement notes, Indigenous community Healing Person.

252 LCO Engagement notes, Indigenous community Healing Person.

253 LCO Engagement notes, Indigenous health care centre staff.

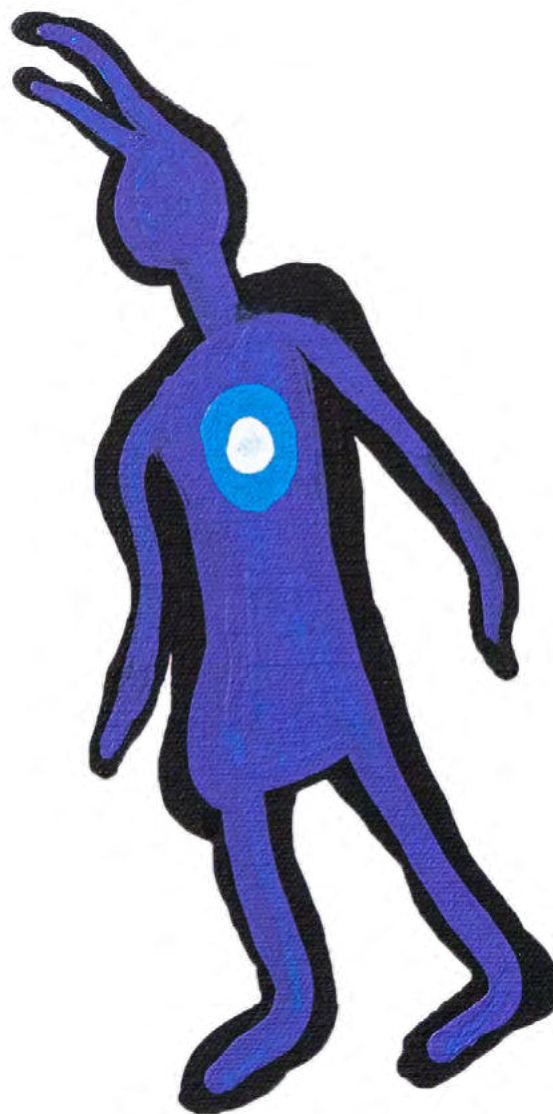
254 LCO Engagement notes, Indigenous health care centre staff.

When it works, the experience can be a very positive one for all:

*I know one doctor she sits down with you talks about diabetes. But if the patient says no, I know an elder, and the elder says drink this or do this, as long as its not going to be imminent death, our practitioner gives them latitude to do that. Do that for a month she says and we'll come back and see how it works.<sup>255</sup>*

*Part of what I can say is a good experience. During my uncle having heart procedure I had to drive back and forth between Sudbury and Ottawa. But I remembered to bring the smudge, and medicine, and all these things we will need. When I walked-in to the hospital I was overwhelmed with the stress of thinking my uncle might die. Then I saw there was a picture and it looked Indigenous. I read the caption and it invited me to use this space in a nice welcoming message. The room was designed properly for our needs. It is a round room with a medicine supply, with ventilation. I spent a lot of time in that space. It is a quiet and welcoming space, with no interaction with service provider. I didn't need permission, and it made all the difference... It was respectful space, no one had to help me. It wasn't locked. I didn't have to ask permission. Taking away the bureaucracy to it. There are other spaces where you have to ask where the key is.<sup>256</sup>*

*A Birthing Centre got access to traditional medicines for mothers and babies, and the LHIN is actually now funding traditional medicines programs such as ceremonies and medicines. The barrier comes back to the historical racism and not valuing the systems. ... We don't need Western research to know and accept the validity of our practices and medicines.<sup>257</sup>*



255 LCO Engagement notes, Indigenous community Elder.

256 LCO Engagement notes, Indigenous health care centre staff.

257 LCO Engagement notes, Indigenous health care centre staff.

## Promising Directions for Future Law Reform

5. Address racism and discrimination as barriers to care by exploring legal and financial structures that can promote more autonomously delivered or self-determined Indigenous health care programs and services on behalf of both the provincial and federal governments.
6. Address racism and discrimination as barriers to care by ensuring a higher proportion of Indigenous health care staff, including those in positions of senior leadership.
7. Ontario Health Teams should regard compliance with Ontario's Human Rights Code, the TRC Calls to Action, and UNDRIP as important as other health care standards and requirements.
8. Mandate a formal provincial wide policy to allow Indigenous traditional or spiritual services (ex. smudging, drumming) in health care institutions.
9. Explore the development of Indigenous "culturally relevant indicators" across both provincial and federal frameworks to change the way health care services are defined, measured and billed, and to create a way to measure the performance of the system in achieving culturally competent service by staff and the creation of culturally safe spaces.
10. Explore ways to make Indigenous Patient Navigators widely available, especially across provincial and federal programs and services, in off-reserve and urban areas, and include the Patient Navigators in Health Team planning and critical incident debriefs.
11. Explore ways in which health care service and professional regulators and oversight mechanisms, including adjudicative bodies, can work with Indigenous communities to develop meaningful, effective, and responsive complaints and investigation mechanisms. This should involve both the federal and provincial ministries or adjudicative bodies where there is shared jurisdiction, such as the Canadian Human Rights Tribunal, Federal Court, and where health care professionals may be employed by federal ministries or agencies or by First Nation Band Councils.
12. Find ways to train health care professionals in both cultural competence and cultural safety, the latter of which pays explicit attention to power relations between service providers and users. This should involve both provincial and federal governments as some health care professionals may be employed by federal ministries or agencies or by First Nation Band Councils.

Steps that the province of Ontario could take to further these goals:

- Identify regulatory mechanisms to prioritize Indigenous community representation in senior positions of responsibility, resource allocation, and decision-making in health care services and planning tables, such as at LHINs and Ontario Health Teams.
- Explore the creation of Indigenous Health Teams as a distinct initiative and goal of the Ontario Health Team development process.
- Actively engage Indigenous communities like NAN in creation of their own health care systems wide policy to allow Indigenous traditional or spiritual services (ex. smudging, drumming) in health care institutions.
- Explore health care service funding models that take in to account local dispute resolution options within Indigenous communities.
- Review the scope and mandate of health professions and services review boards in developing new models for dispute resolution that take in to account Indigenous health practices and needs.



## C. Reconceiving Health Care Consent, Capacity, and Substitute Decision Making

People in the last stages of life may not have the ability (capacity) to direct (consent) to their health care at all times. Together, the *Health Care Consent Act, 1996* and *Substitute Decisions Act, 1992* govern informed consent, advance care planning (ACP) and substitute decision-making (SDM) in Ontario. But this is only the beginning of the story. The legislation is interpreted and applied through a wide array of other legal and quasi-legal instruments, as well as through the lens of federal jurisdiction touching on marriage, divorce, mental capacity and related issues.

For instance, within Ontario and other provinces there is a growing body of case law which interprets challenging scenarios where consent, capacity, and SDM decision making are called into question, such as withholding or withdrawing life-sustaining treatment, interpreting wishes related to “do not resuscitate” emergency CPR, or the provision of artificial nutrition and hydration during palliative sedation.

Case law may in turn influence the policies and practice standards enacted by professional regulators such as the College of Physicians of Ontario (CPSO), the College of Nurses of Ontario (CNO), or policies and guidance provided by professional liability insurers such as the Canadian Medical Protective Association (CMPA). Facilities such as hospitals or long-term care facilities may develop local policies or provide information materials, forms or other supporting material that may, intentionally or otherwise, shape the choices patients and families make.

Legislation can also be quite convoluted to understand and follow. In plainer language, the process of obtaining informed consent consists of several steps:

1. Assessing and confirming that the patient is capable with respect to the proposed treatment, insofar as they are able to
  - understand relevant information about the proposed treatment, and
  - the reasonably foreseeable consequences of accepting or rejecting the proposed treatment.
2. That there are no “reasonable grounds” to question the patient’s capacity to make the decision.
3. And that any consent is given voluntarily and properly informed, meaning that the patient receives relevant information that a reasonable person in the same circumstances would require, including expected risks and benefits, alternative courses of action, and likely consequences of not having the treatment.”<sup>258</sup>

The picture is further complicated by the contours of provincial and federal jurisdiction. For instance, the federal government has jurisdiction over “Marriage and Divorce” under s. 91(26) of the Constitution Act, 1867 and the federal *Indian Act* also has relevant provisions relating to the descent of property, wills, estates, mental incompetency, and guardianship of children.<sup>259</sup>

### i. Consent and Capacity

LCO’s Last Stages of Life Discussion Paper identified many concerns arising from the law of consent, capacity, ACP and SDM in context of palliative and end of life care.<sup>260</sup> This area of law stood out as one of the most frequently discussed areas within LCO’s Last Stages of Life public consultation process.<sup>261</sup>

It was also a major concern for Indigenous communities. In many cases, we were told how the legislation silences Indigenous patients, their family

<sup>258</sup> See HCCA s. 4, 10, 11

<sup>259</sup> See for example *Indian Act* ss. 42-52.5.

<sup>260</sup> For more information see The LCO’s *Improving the Last Stages of Life Discussion Paper* (May 2017) at chapter 4.D and 6.B. Please also see the findings and recommendations made in the LCO’s recently completed *Legal Capacity, Guardianship and Decision-Making Final Report* (March 2017), online: <https://www.lco-cdo.org/en/our-current-projects/legal-capacity-decision-making-and-guardianship/>.

<sup>261</sup> See the Last Stages of Life Final Report (July 2021) “Provincial Consultations” at 12-17.

members, and communities. The discretionary nature of many of the legislated terms – such as “reasonable grounds” to question capacity to make a decision, decisions made relative to a “reasonable person” or “reasonably foreseeable” – are imbued with Western assumptions about these kinds of values. Indeed, the LCO was frequently told that basic cultural and traditional practices frequently fall outside a plain reading of the basic legislative scheme:

*How does a colonialist notion of palliative care impact or influence consent? It is coercive, people are going along with it because they're trying to protect themselves in part. It isn't real informed consent. I don't think most people know that they can change their mind. Discussing consent – are the risks shared every time? The way consent actually happens at the bedside doesn't even meet the current standard – nurses can't really fully explain all side effects and consequences but getting consent it being dumped off on to them. Indigenous experience in the Canadian health care system has created such an imbalance of power that even if its us providing care in their homes we're still carrying the fact that we're Western health care providers. There's so much to undo to get someone to the place where they feel they have control. It's not consent when you're in the time of reflection. Consent is also supposed to include offering and considering alternatives – so how are Indigenous medical services offered or considered as alternatives? They aren't.<sup>262</sup>*

Health system studies have noted how Indigenous participants anticipate that being identified as Aboriginal and poor might diminish their credibility or reduce their chances of receiving help. This was such a common experience that participants often had to

strategize how to manage negative responses from health care providers in advance of accessing care.<sup>263</sup> The LCO also heard that assumptions embedded in legislation also work to silence Indigenous perspectives by normalizing what health care conversations should address, how long they should take, how they should be done “efficiently.” These assumptions are often anathema to Indigenous experiences, and underlying trauma:

*I've had traumatized clients and sometimes it takes them years to build trust an open up and talk to me. There's a need to build the relationship. And in fact this is one great gift I've learned as a nurse from Indigenous communities: the importance and role of storytelling. It makes a huge difference for my client to tell the story and this is what often gets the treatment team to be more responsive.”<sup>264</sup>*

Indigenous worldviews often conflict with the legislative scheme. For example, in an Indigenous worldview, the “reasonable information necessary to make a decision” might include readily accessible traditional foods, medicines or rituals – none of which may be acknowledged by a health care provider, offered for inclusion as a course of treatment, or meaningfully accommodated within a particular facility. Health care providers might also seek consent during a time of reflection when decisions are not supposed to be made. Finally, to an Indigenous person, “reasonably foreseeable consequences” might include how a decision impacts an entire community, suggesting that the community itself may need all the “relevant information” to make the decision collectively. Urgent circumstances or simple convenience may diminish or eliminate the validity of such views. If and when an Indigenous person or community insists, the health care provider may become hostile, and the competence of the patient or SDM may be called into question.<sup>265</sup>

<sup>262</sup> LCO Engagement notes, Indigenous health care centre staff.

<sup>263</sup> Wellesley 2015.

<sup>264</sup> LCO Engagement notes, nurse providing care in community hospice.

<sup>265</sup> LCO Engagement notes, Indigenous community member.

## ii. Substitute Decision Making

One community has been actively finding ways to reframe consent as a collective or network decision-making process that involves the presence of community members. Members of the Akwesasne community spoke to developing ways of ensuring culturally safe decision-making as requiring important community members to be present, especially in situations of power imbalance. Frontline workers were seen as key here because they are knowledgeable about individual cases and receive management support as an important part of the decision-making process.<sup>266</sup>

These kinds of barriers extend into other aspects of obtaining consent. Under the HCCA, where no SDM has been identified and chosen in advance, legislation sets out a hierarchy of people who can act as SDMs. In descending order of rank, the list names:

- Guardians of the person;
- An attorney named in a power of attorney for personal care;
- Representatives appointed by the Consent and Capacity Board (CCB);
- A spouse or partner;
- A child or parent;
- A sibling;
- Any other relative; and finally;
- The Public Guardian and Trustee.

Again, for some Indigenous communities, this list represents a very Western conception of familial hierarchy, community, and the authority of various formally defined legal instruments (such as court-appointed guardians or powers of attorney).

This hierarchy also contradicts the decision-making process in some Indigenous communities who may take a collective or consensus-based approach to providing substitute decision making. This approach is not currently envisioned or readily accommodated under the legislation.

This hierarchy also indicates a trust in government as the “decision maker of last resort.” For many Indigenous people, a history of colonial and institutional trauma makes such trust impossible, while again negating the role the Indigenous community may instead have a legitimate decision maker. This trauma is continuously re-inscribed by design in some cases. Some communities noted that patient incapacity status still requires registration with INAC, who have to certify and register the incapacity under the *Indian Act*.<sup>267</sup> This may not be required where the person already developed legal instruments like a power of attorney. But it does require such (Western, legalistic) steps to be taken ahead of time, and to adopt the legislated model of designating substitute decision makers contrary to more collective or community-based approaches.

## iii. Best Interests Decision-Making

SDMs are expected to make decisions consistent with “best interests” of the patient, failing which, they may be threatened with, or actually removed from, their role on application to the CCB. The question of what “best interests” means to Indigenous communities can be quite varied, and without adopting a culturally competent lens, may appear to run contrary to the interests of the patient. For example, “best interests” might include the interests and impact on the wider community, as well as the patient. What are the patient’s “best interests” where they prefer to remain in community and dying at home and thus rejecting curative and symptom relieving care? Or, as was recently explored in *Hamilton Health Science Corp. v. DH*, when is a parent acting contrary to best interests in rejecting Western medicine in favor of traditional medicines, despite the former having a 95% chance of curing childhood leukemia? And is this notion of best interests compatible or incompatible with traditional laws which hold the best interests of their children as a core belief?<sup>268</sup>

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266 LCO Engagement notes, Indigenous health care centre staff.

267 LCO Engagement notes, Indigenous health care centre staff.

268 See above discussion in chapter 4.D.

The case is particularly illustrative of these tensions. At the heart of *Hamilton Health Sciences Corp v D.H* was concern over whether a child with cancer from Six Nations of the Grand River (J.J.) should be treated with chemotherapy.<sup>269</sup> Her mother considered chemotherapy to fall outside the bounds of traditional medicine and, after initially consenting to and commencing treatment, withdrew that consent to treatment on J.J.'s behalf. The treating physician and health facility disputed the mother's authority to make this decision as a matter of child protection and the Brant Family and Children's Service became involved. The treatment was cited as giving the child "a 90 to 95% chance of being cured" while "the specialists at the applicant hospital are not aware of any survivor without chemotherapy treatments."<sup>270</sup> In the first instance, the court recognized a section 35 Aboriginal right in the area of traditional healing practices and allowed for J.J.'s mother to reject treatment. However, this judgement raised serious concerns about the balance between child protection and Aboriginal rights, and the Attorney General for Ontario became involved in a motion before the presiding judge. The judge subsequently amended his reasons stating instead that:

*implicit in this decision is that recognition and implementation of the right to use traditional medicines must remain consistent with the principle that the best interests of the child remain paramount. The Aboriginal right to use traditional medicine must be respected, and must be considered, among other factors, in any analysis of the best interests of the child, and whether the child is in need of protection.*<sup>271</sup>

The judge went on to note that "it does no mischief to my decision to recognize that the best interests of the child remains paramount" in part because one of the core tenants of Haudenosaunee culture and society "is the ultimate respect accorded to their children. They are considered gifts from the Creator."<sup>272</sup> Subsequently, the judge went on to describe how

*the province and the family collaboratively worked to form a health care team to bring the best both had to offer to address J.J.'s ongoing treatment. This approach recognizes the province's acceptance of the family's right to practice traditional medicine and the family's acceptance western medicine will most certainly help their daughter. It is simply a recognition of what is in J.J.'s best interest. Such an approach bodes well for the future.*<sup>273</sup>

It follows from the important discussion in this case that there is an opportunity to create space for Indigenous conceptions of "best interest" decision making. The approach of some communities might include a collective or decentralized decision making in health care. LCO's earlier work reviewing the law of capacity, decision-making and guardianship explored concepts like "supportive decision-making".<sup>274</sup> Elsewhere, commentators have considered approaches to "networked" or "collaborative" decision making.<sup>275</sup> Under international instruments like the *International Convention on the Rights of Persons with Disabilities*, the notion of "incapacity" is called into question, and instead framed as always being a question of accommodation and support.

269 *Hamilton Health Sciences Corp v D.H* (2014 ONCJ 603) and as amended in (2015 ONCJ 229) (HHS).

270 HHS at 2.

271 HHS at amended para 83(a).

272 HHS at para 4.

273 HHS at para 5.

274 See LCO recommendations concerning supportive decision-making in *Legal Capacity, Guardianship and Decision-Making Final Report* (March 2017), online: <https://www.lco-cdo.org/en/our-current-projects/legal-capacity-decision-making-and-guardianship/>.

275 See for example Janet Jull et. al., "Shared decision-making and health for First Nations, Métis and Inuit women: a study protocol" (BMC Med Inform Decis Mak. 2012; 12: 146), online: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3541952/> (Jull 2012); and Janet Jull et. al., "Shared Decision Making with Aboriginal Women Facing Health Decisions: A qualitative study identifying needs, supports, and barriers" (Intl J Indigenous People 11:4, 401-416), online: <https://journals.sagepub.com/doi/10.1177/117718011501100407> (Jull 2015).

The importance of addressing legislative gaps was highlighted by several participants:

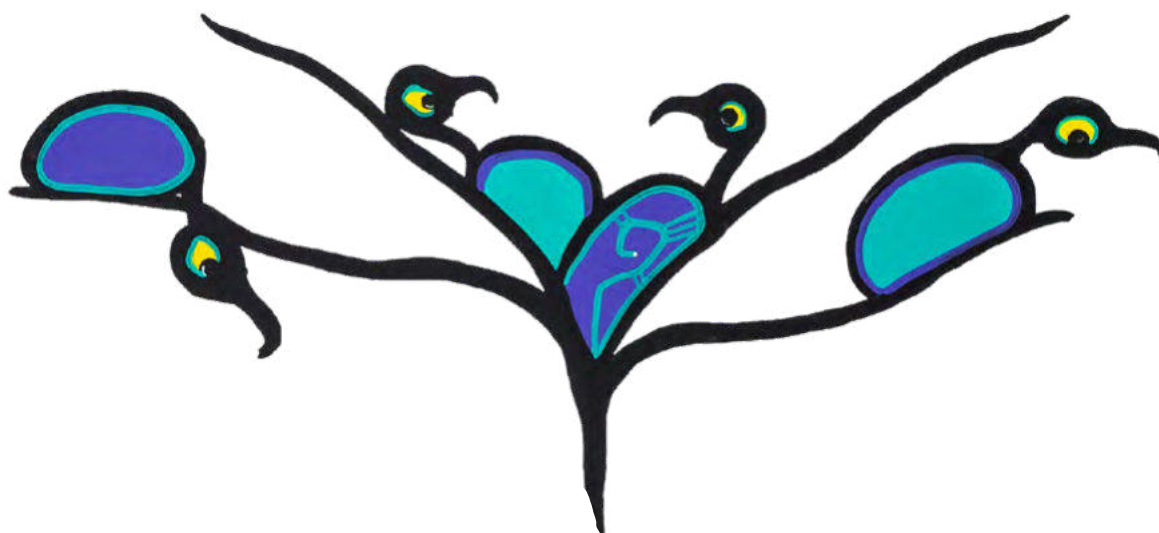
*I was fighting for this one [Indigenous] guy in ICU and the team were putting tubes in everywhere and he had no family but I knew it wasn't what he'd want. Eventually the doc called late in the night to say we've decided that you (a registered nurse) do know him best and can make decisions for him. I have end-of-life discussions with all my clients. But hospital doesn't get into those kinds of discussion. People living on the street have your street family but on paper they're not. The hospital doesn't want anything to do with these street involved SDMs. it's just prejudice. Hospitals are very old school. If I'm involved I can communicate it to the health team but they won't listen to me because I'm not supposed to act like a SDM. [...] We need to put it in the law that nurses and support organizations can act as SDMs. The hospitals default is otherwise to do everything [medical intervention]. My sense is that especially at teaching hospitals they do the full intervention because it supports the research at the hospital. The consequence of this is suffering.<sup>276</sup>*

A similar example was shared by another participant. She noted that despite the dire condition of the patient near the end of his life, the treatment team was prepared to act with every available medical intervention. This, she knew, would be contrary to the wishes of the patient, but she felt helpless to intervene:

*[Name] was navy blue up to his hips and they were rolling in the dialysis machine. He had a bad wound on his leg and it [dialysis] would take two hours. But we knew him his whole life and even earlier took care of [name's] wife who had died of HIV. And the Indigenous community who came to see him felt totally overwhelmed.<sup>277</sup>*

#### iv. Powers of Attorney

Concerns were also raised in relation to the kinds of existing legal instruments that support health care consent and substitute decision making, including powers of attorney for personal care (PofAPC) and powers of attorney for property (PofAProperty), and advance care planning (ACP). Formal ACP and PofA was noted as taking too long to develop, of not being talked about, or being in conflict with community care approaches and care models of reciprocity.



<sup>276</sup> LCO Engagement notes, nurse providing care in community hospice.

<sup>277</sup> LCO Engagement notes, nurse providing care in community hospice.



As one participant put it:

*The process to get POA appointed takes too long. There's a lack of guidance on what to do next and that leads to delays. When respite patients come in [for an initial consultation] they learn about the issues, it's a soft entry into our place so they get to know our faces and sounds. They do another trip to visit with us, and then it is a respite stay when they finally come in. But in the meantime they need a POA but there is an eight-month wait, and this is too long. And for the POA there is nothing to prep the patient and the family like what we do. In our culture we don't talk about end-of-life care. So they gave up, said I can't handle this anymore, help me go peacefully with MAID.<sup>278</sup>*

These instruments may fail to accommodate Indigenous wishes, values, and beliefs in relation to obligations of SDM and other family / community members. And the existing legislative role for “wishes, values and beliefs” under the HCCA may be rendered secondary or trumped by concepts like “best interests” and “medical futility” that withholds potential treatment or, conversely, by a “medical standard of care” that imposes potentially unwanted treatment.

Several participants shared such experiences:

*Years ago when I worked at [a] hospital, there was a blitz substitute decision making, but there was packages, I don't know it seemed to be better than, at least brought to social workers and have conversations with families. You saw those packages from attorney general, you had the conversation at least, if somebody says I don't know who would, you could pull social worker in, that's my experience use to be more discussion. We always struggle with community they want to designate six children, when you start to get that back and forth, when the team is able to sit down with family then it's successful, they have to be in person, start at beginning.<sup>279</sup>*

*I feel like I broke PHIPA all the time at the long-term care home because I wasn't following the PofA but rather giving information to the right [Indigenous] family member and the family circle of care.<sup>280</sup>*

Powers of attorney and other legal instruments can also create the apprehension of “non-compliance”:

*The long-term care home required a power of attorney to be on file, ignoring the traditional [Indigenous] order or who is actually participating or what the community conceptions are of who is in the position of trust or consensus. These are traditional rights, perhaps even international or federal rights. And the facility feels torn in how to manage these conflicts and mediate because their performance measures and expectations are tied to funding so they feel compelled to act as agents of the Western order.<sup>281</sup>*

278 LCO Engagement notes, Indigenous health care centre staff.

279 LCO Engagement notes, Indigenous health care centre staff.

280 LCO Engagement notes, Indigenous health care centre staff.

281 LCO Engagement notes, Indigenous health care centre staff.

Several participants also spoke to the efficacy of more formally adopting public education techniques to help train front-line workers and health system administrators on Indigenous conceptions of health care consent and substitute decision-making. It was felt that this helps make the use of legal instruments like powers of attorney more meaningful for Indigenous people.

*Public education, of everyone, would really take a lot of the burden of front-line services. That was the goal of CCB, they were saying we'll pay you half day, go speak to group, in different groups, they weren't going to tell us who to do it with, but something changed and shut it down. Something like that, it would be very cost effective in the end. It would save so many people heart ache.<sup>282</sup>*

## v. Public Guardian and Trustee

Finally, some Indigenous communities pointed out how having the PGT as institutional decision maker of last resort revisits a colonial history defined by institutional abuse, mistrust, violence and trauma.

This trauma runs very deep. Several participants shared their experiences:

*One of our clients had a number of issues with institutions and was traumatized by all of them. She had a small support group, she lost her home, she lost everything she owned, she was preparing for it, she knew she was going to die. But she was choosing not to go to hospital system, she was choosing to go to an alley to die alone. And she did. Because of her institutional trauma.<sup>283</sup>*

*Recently we had someone in hospital who wasn't able to speak. The PGT came into play and marginalizes their experience. The PGT was treatment focused. They knew this individual did not want to take meds but the person was well-intentioned and was making decisions that put us all in awkward position. The patient's partner didn't have a POA and weren't in a common law relationship so the institution and PGT said she shouldn't make decisions for him. He ended up dying here, in a hospital that was very strict [re Indigenous practices], very hard.<sup>284</sup>*

*The PGT doesn't know people. They just do the default treatment. They'll impose all the treatment the docs offer. PGT came in for [name] on life support and he was unconscious at that point. We as nurses and all the Indigenous groups supporting [name] were being ignored. Other problem is if you are going into hospital and street involved you will take a hit of drugs before you go in. But drugs are a recognized disability and needs to be accommodated and not discriminated against. But the hospital is not treating them appropriately.<sup>285</sup>*

Building a relationship of trust and understanding between the community and PGT was noted in Akwesasne, reinforcing the importance of supporting knowledgeable frontline workers:

*The PGT person is isolated from community by and large – no relationship there and no relationship-building component which would alleviate this issue. If they were in community and not Ottawa they may come to visit. If the person has a family member or POA to advocate for them that might help, otherwise it's difficult to access that PGT person.<sup>286</sup>*

282 LCO Engagement notes, Indigenous health care centre staff.

283 LCO Engagement notes, Indigenous health care centre staff.

284 LCO Engagement notes, hospice social worker.

285 LCO Engagement notes, nurse providing care in community hospice.

286 LCO Engagement notes, Indigenous health care centre staff.

Instead, some Indigenous communities have developed their own extra-legislative process, effectively creating their own guardianship system or calling for a community-based PGT person:

*Right now there's no PGT person in our community. The nearest person is hours away in Ottawa. It's difficult to access that PGT person. Sometimes they come in person, sometimes they don't. There's no relationship there. We need our own PGT person. Right now we don't even bother with the PGT, and instead the council sometimes does that role.<sup>287</sup>*

*My biggest beef: we need a PGT person for our own people. As it is, the PGT person is loaded – there are gov't / trust issues.<sup>288</sup>*

## vi. Advance Care Planning

Communities also raised concerns with the role of “advanced care planning” (ACP). ACP is a process that involves a person identifying and choosing a SDM and sharing the wishes, values and beliefs that an SDM must interpret when making decisions on the person’s behalf. Legislatively it resides in the *Health Care Consent Act* across several sections, including as a criterion required for an SDM to make “best interests” medical decisions on behalf of an incapable person by relying on their last known wishes, values and beliefs.<sup>289</sup> Research and experience prove that advance care planning conversations improve patient and family satisfaction with end-of-life care. These processes aim to ensure alignment between a person’s values and treatment; lessen family distress; decrease hospitalizations and admissions to critical care; and decrease unwanted investigations, interventions and treatments, among other benefits.

The LCO heard that Indigenous communities are much less likely to experience these benefits.

It is unclear, for instance, how an Indigenous community could use advance care planning to indicate that a community should participate in substitute health care decision making rather than just one or two people. Indigenous communities may be inclined to a more holistic approach involving an entire family or community. There is also reluctance associated with the idea of discussing and thinking about future death. In this regard the requirements, benefits, and protective functions of ACP under the HCCA remain inaccessible to some Indigenous communities as it is currently formulated:

*I go back a bit to the ACP – it's a lot of what I teach. Talking about the hierarchy and how it doesn't really fit this community. Its very large families, or the community itself is supporting the patient and that's not reflected in the hierarchy.<sup>290</sup>*

ACP can also be misleading and cause confusion where it is not culturally specific or accessible. ACP can also have a unique role in Indigenous communities because of the emphasis on personal relationships and trust building and an ongoing process. This extends to medical relationships.

*What kind of time is needed? How do you do ACP, or journey planning, and how does that look in a way that serves this community? Time is needed to build relationships and build the trust. Otherwise people won't talk to you. Need earlier visits and trust building even before someone is sick because you often have to repair the relationship. Care needs and not linear.<sup>291</sup>*

287 LCO Engagement notes, Indigenous health care centre staff.

288 LCO Engagement notes, Indigenous health care centre staff.

289 HCCA s. 21(2).

290 LCO Engagement notes, professor of Indigenous health care.

291 LCO Engagement notes, professor of Indigenous health care.

Projects including the Queen’s University-led are making significant efforts to adapt ACP tools to suit the needs of Indigenous communities.<sup>292</sup>

*I was part of the care team for a man who was very knowledgeable about our ways. He spent most of the time educating us. When the time came he and the family knew us and trusted us. So at the end we could make it happen the way he wanted it to happen. That’s a TRC moment on Indigenous knowledge transfer. It should be in their time, not our time. And this links back to this notion that we locally are the first point of contact. There are four groups of providers in community, and so it can’t be one persons responsibility; and it should be shared so that the next care provider can build on it and pick up the thread.<sup>293</sup>*

*Communities can do advance care planning themselves but would be good if they had training.<sup>294</sup>*

*I was talking to the nurse when my aunt was sick, she was not interested in hearing about the room downstairs, she didn’t ask me about my aunty wanted, she wouldn’t have the awkward conversation. This is non-compliance; wishes and beliefs are one of the things in scope of advance care planning. I have one [a will] but you have to pay for it so a lot of people don’t bother.<sup>295</sup>*

ACP and earlier identification of needs is encouraged. But non-status Indigenous people feel disconnected and that it is unsafe to self-identify, which prevents access to end-of-life care. This raises additional issues with status to be explored subsequently.

## vii. Indigenous Patient Navigators

Many other approaches suggest that an “Indigenous lens” of “cultural competence” can be brought to bear as a way of interpreting or accommodating Indigenous world views into existing legislation and health care systems. As highlighted in the introduction, a frequent criticism of this approach is that it places a disproportionate burden on the equity-seeking group to constantly assert their difference. It requires constant resistance, and nearly endless resilience, that can be exhausting. It also renders traditional Indigenous practices as an act of permission or the exception from underlying rules and norms.

One promising direction for addressing the issues raised in this section are Indigenous Patient Navigators. As one service provider put it:

*Facilities should be obliged to get the instruction from the patient as to what their wishes are. But if you aren’t well it’s hard to do any of this or understand any of this. They need an advocate to sit and talk to them and help them with all this. Hospitals need this and it needs to be proactive. [Our facility] does this, we take the time to talk to people. But someone not [eligible for our care] was begging to die here because we are caring. Hospitals are also doing acute care - the model is catch and release. They’re not suited to this so need people to help them like an external advocate.<sup>296</sup>*

292 See Jull 2012, 2015, above.

293 LCO Engagement notes, Indigenous health care centre staff.

294 LCO Engagement notes, expert in Indigenous health policy.

295 LCO Engagement notes, Indigenous community member.

296 LCO Engagement notes, nurse providing care in community hospice.

The potential and importance of Patient Navigators in general is highlighted as a central recommendation in the OPCN *Delivery Framework*. In OPCN's community-driven development model, Elders are recognized as the core of the palliative program who "know how to look after our people and who value that model of care."<sup>297</sup> One elder noted that the colonial approach to medicine and medicalization biases the services against traditional roles, like that of elders. Instead, "there should be legal language to make space for the Elder to participate [in palliative care], and in consideration of who the community thinks their Elders are."<sup>298</sup>

The importance of Elders is also intergenerational:

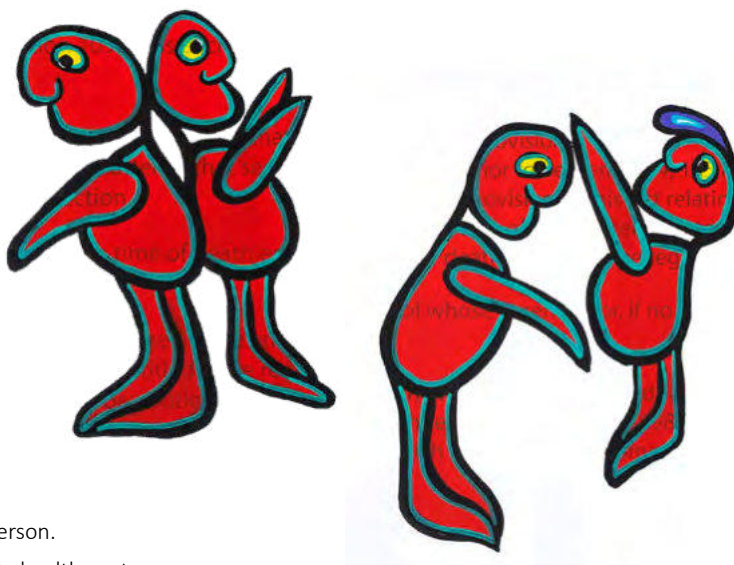
*There was a generation that was skipped. Grandparents know these practices but my parents sort of don't. They don't practice as much as they should whereas I learned from my grandparents as peers. But there's not much that is supporting those roles. Maybe there's six people in the whole community who can conduct the ceremony. Also conducting thanksgiving, medicine, and other ceremonies. To have the numbers who could support and grow that knowledge is where the focus should be.*<sup>299</sup>

In addition to an expanded role for Elders, engaged participants highlighted the important and effective role Indigenous Patient Navigators can have:

*We have to volunteer all our time; and you have to spend all the time educating the person who is supposed to be your advocate. What's the right model to formalize this? The hospitals should have to fund it. Their complaints systems don't work for us. Instead the hospital should hire the Indigenous patient navigator and each one should have one. The burden of education and advocacy is always pushed back onto the community. But this hospital advocate would have to have some authority, quasi-independent or reporting to the Board if not the CEO.*<sup>300</sup>

One policy person noted that recognition of traditional practices and roles is often only facilitated where there is someone to advocate for it, and who knows how to navigate the hospital administrative systems and personnel effectively:

*My experiences is that they respected my culture and bringing in Indigenous care providers, but only if there is someone to advocate for the family.*<sup>301</sup>



297 OPCN 2019 at 40-46.

298 LCO Engagement notes, Indigenous community Elder.

299 LCO Engagement notes, Indigenous community Healing Person.

300 LCO Engagement notes, nurse providing care in community health centre.

301 LCO Engagement notes, expert in Indigenous health policy.

One participant noted that there is a balance to be struck in formalizing such roles. While recognition on a systemic level is good, an overly prescriptive approach to defining roles for Indigenous people would be counter-productive. A positive example was given about the approach to regulating Indigenous midwives in Ontario. While formally recognized, Indigenous midwives are exempted from Ontario's legislated regime for regulating midwives:

*It's a balance between recognition but not looking for regulation from Ontario government. What is the health practices of people and communities, with traditional health looking to harmonize both, exist in separate entities and see how they can harmonize together.<sup>302</sup>*

A policy participant noted that this is an example of a larger concern in the tension between recognition, legal or regulatory specificity, and remaining flexible. This is what is required for local practices and traditions to flourish:

*Government is going to be like "I don't understand this," but they don't need to understand every practice. Our physicians have said the very same thing: to make the space to allow those practices by community, each community has their own law, and practices, what they come up against is a lack of recognition. There's no recognition of the family, the elder, or the medicines. The community needs to be in the driver's seat in designing the model of care.<sup>303</sup>*

## viii. Conclusion

As foundational as the *Health Care Consent Act* is to the provision of health care in Ontario, it is equally as foundational to reconciliation with Indigenous communities. The *Act* makes universal assumptions about who makes decisions, how decisions are made, the ways in which decision making is (and is not) supported, and what good decisions look like. But this universality has the effect of excluding many traditional Indigenous approaches to these same questions. This exclusion pervades all aspects of the health care system. It means, practically and philosophically, that many Indigenous people are on the outside looking in and burdened with the responsibility to assert traditional views at every step.

This chapter highlights promising intersections where colonial law might be set aside and where Indigenous self-determination and reconciliation can flourish. This includes:

- More collective and collaborative approaches to health care decision making and substitute decision-making;
- Recognition of community authority to serve as a "guardian of last resort;"
- Changes to legal instruments like Powers of Attorney, or the elimination of the need for such instruments in Indigenous communities;
- Care planning that aligns Indigenous conceptions of supporting transitions back to the spirit world that include a much more holistic and community-based approach; and
- Formal recognition of the role of Elders and Patient Navigators in the health care system with necessary flexibility in their roles and approaches.

302 LCO Engagement notes, expert in Indigenous health policy. Midwives are otherwise regulated under the *Regulated Health Professions Act, 1991*; the Health Professions Procedural Code (which is Schedule 2 to the RHPA); and the *Midwifery Act, 1991*. In addition there are specific regulations made under both the RHPA and the Midwifery Act.

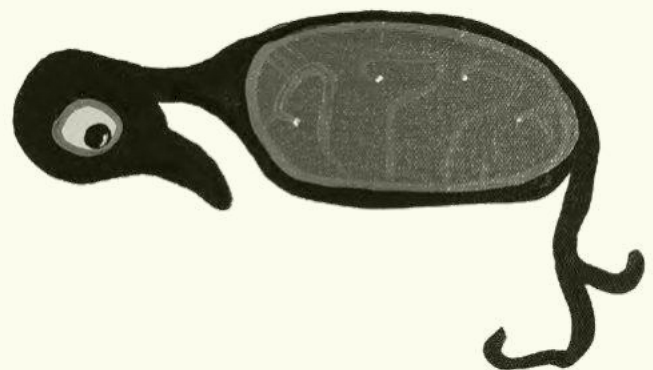
303 LCO Engagement notes, expert in Indigenous health policy.

## Promising Directions for Future Law Reform Conversations

4. Review key provisions of the HCCA and SDA related to consent, capacity, best interest, ACP, “reasonable information” and substitute decision-making through Indigenous lenses. Consider alternate approaches that take into account more collective and community-based decision making, the time of reflection, Indigenous knowledge, and traditional laws for decision making.
5. Discuss a dispute resolution model for the kinds of decision-making issues arising under the HCCA and SDA that work for the local community.
6. Examine the role of the government institutions as “decision makers of last resort” in favor of local solutions and protocols and a role for the community.
7. Examine the role of formal and legislatively mandated legal instruments in both federal and provincial instances over Powers of Attorney for Personal Care, court-appointed guardians, and common law spouses in favor of traditional laws and approaches to these kinds of needs and relationships.
8. Expand the system-wide role for Indigenous Patient Navigators to assist as cultural translators and with all aspects of identifying care options, cultural and spiritual values and practices, conversations about consent and capacity, longer-term care planning around personal and community wishes, values and beliefs, etc. Consistent with shared responsibility for health care this should be explicitly coordinated between both the federal and provincial services, funding and programming.
9. Ensure advance care planning is designed to take into account the longer-term care planning around personal and community wishes, values and beliefs.

Steps that the province of Ontario could take to further these goals:

- Explore health care service funding models that take in to account local dispute resolution options within Indigenous communities.
- Review the scope and mandate of health professions and services review boards in developing new models for dispute resolution that take in to account Indigenous health practices and needs.
- Explore options to remove mechanisms in the HCCA and SDA and return substitute decision making to Indigenous communities.
- Expand Indigenous patient navigation services.
- Consistent with recommendations in LCO’s LSL Final Report, review the HCCA provisions related to “advance care planning.” Consider formalizing these definitions and creating flexible definitions that are culturally and linguistically responsive to the needs of Indigenous Communities and their views on “palliative” care.
- Consistent with recommendations in LCO’s LSL Final Report, foster the development of a public health promotion approach to palliative and end-of-life care that would support Indigenous communities in defining their own approaches to palliative care.



## D. The Impact of Jurisdiction on Jordan's Principle and Equitable Access to Health Care

Many engaged groups spoke of the difficulties, and risks, of status identification and jurisdictional issues that play out in health care coverage between the federal and provincial governments. A proper understanding of current institutional arrangements highlights how Indigenous persons both in and outside of community are forced to navigate a complex scheme of services. This is particularly the case of urban Indigenous residents.

The primary means by which the federal government has sought to improve Indigenous health outcomes is the FNIHB, currently under the jurisdiction of the recently created Department of Indigenous Services Canada (DISC), having been transferred there from Health Canada in August 2017.<sup>304</sup>

FNIHB, as part of its core mandate, oversees implementation of the Health Transfer Policy (HTP) to “enable Indian Bands to design health programs, establish services and allocate funds according to community health priorities,” and thereby seek to remedy health-related disparities historically and disproportionately faced by Indigenous people compared to non-Indigenous Canadians.

With respect to continuing care on-reserve and home care, the federal government, through ISC, administers the Non-Insured Health Benefits (NIHB) program, which is designed to provide benefit and service coverage for

status First Nations and recognized Inuit not covered by provincial, territorial, or private health insurance plans. Additionally, the federal government funds and administers a range of Indigenous-focused programs to support home and community care, assisted living, disease and substance abuse prevention, prenatal health, nutrition, early literacy and learning, children's physical and oral health, and mental wellness as well as training for health professionals to work with Indigenous communities.

The NIHB program is an important source of health care coverage for recognized Inuit and status First Nations communities. It provides certain medically necessary services to these clients regardless of residence or income. Eligible Inuit and First Nations peoples may qualify for “a specified range of medically necessary health-related goods and services [that are] not covered through private insurance plans or provincial/territorial health and social programs” including “prescription drugs, over-the-counter medication, medical supplies and equipment, mental health counselling, dental care, vision care, and medical transportation.”<sup>305</sup> Given the principle of shared responsibility as set out in the IHP, when a benefit is covered under another plan, the FNIHB coordinates with that other plan to ensure that obligations to First Nations and Inuit communities are met.<sup>306</sup>

According to its NIHB 2017-2018 Annual Report, the FNIHB stated that it had 867,749 eligible clients—819,977 (94.5%) of whom were First Nations while 47,772 (5.5%) were Inuit.<sup>307</sup> In Canada, the Ontario region accounted for the largest proportion of these clients at 24.2% (210,295 total, or 209,496 First Nations and 799 Inuit).<sup>308</sup> In 2017/18, total NIHB

304 In July 2019, legislation dissolving Indigenous and Northern Affairs Canada and formally establishing the mandates of 2 new departments, Indigenous Services Canada (ISC) and Crown-Indigenous Relations and Northern Affairs (CIRNAC), came into effect.

305 Health Canada, “Benefits Information – Non-Insured Health Benefits” (February 2019), online: <https://www.canada.ca/en/Indigenous-services-canada/services/first-nations-inuit-health/non-insured-health-benefits/benefits-information.html>.

306 Indigenous Services Canada, “Non-Insured Health Benefits – Drug Benefits List January 2019” (February 2019), online: <https://www.canada.ca/en/Indigenous-services-canada/services/non-insured-health-benefits-first-nations-inuit/benefits-services-under-non-insured-health-benefits-program/drugs-pharmacy-benefits/drug-benefit-list.html>.

307 Indigenous Services Canada, “Non-Insured Health Benefits Program: First Nations and Inuit Health Branch: Annual Report 2017-2018” (April 2019), online: <https://www.canada.ca/en/Indigenous-services-canada/services/first-nations-inuit-health/reports-publications/non-insured-health-benefits/non-insured-health-benefits-fnihb-report-2017-2018.html> (ISC Annual Report 2019).

308 ISC Annual Report 2019.



expenditures were \$1.3 billion, which represented an 8.4% increase over 2016/17, or \$101.8 million.<sup>309</sup> Of the 2017-18 total, the three largest expenditures stemmed from pharmacy costs (including medical supplies and equipment) at 39.9% or \$523 million; medical transportation costs (35.1% or \$459.5 million); and dental costs (19.0% or \$249 million).<sup>310</sup>

In assessing these figures, pharmacy costs accounted for the highest percentage of total NIHB expenditures within each region save for in the North and in Manitoba, where costs for medical transportation represented the largest share. To complement provincial and territorial health care programs, including physician and hospice care as well as existing First Nations- and Inuit-led programs and services, the NIHB consistently updates and publishes its Drug Benefit List (DBL) for current and future clients.<sup>311</sup>

For clients diagnosed with a terminal illness and are near the end of life, they will be eligible for supplemental medications available under the Palliative Care Formulary for six months (after which they will have to re-apply if further coverage is required). To receive some or all of these medications, the client (a) must not be receiving care in a provincially covered hospital or a provincially covered long-term care facility and (b) must be diagnosed with a terminal illness or disease that is expected to be the primary cause of death within six months or less.<sup>312</sup>

Despite these programs, the experience on the ground is one of frustration with competing jurisdictional gaps. The play of jurisdictions has a direct effect on self-determination of services and programs:

*It's the same, not much change, we haven't moved that far, dealing with issues blaming Indians for health situation their in. When you get radical and protest you are called a mad Indian. Even if you say "we'll do our own things" you can't do that because you get caught between federal and provincial co-payment formulas, or the province doesn't have jurisdiction on reserve and you can't do anything. There are 14 super agencies (LHINs) in the province that rolled everyone under agencies with nothing for Indigenous review, or voice, despite the fact that Indigenous people live here in this province too.<sup>313</sup>*

*The census did show that 80% of Indigenous live off-reserve in towns and cities. When you frame them as First Nation, Inuit people, and Métis people you exclude urban Indigenous, and so none of them apply or get the services those communities offer.<sup>314</sup>*

309 ISC Annual Report 2019.

310 Other notable expenditures included 2.6% (\$33.6 million) for vision care and 2.5% (\$33.1 million) for mental health. See ISC Annual Report 2019.

311 Indigenous Services Canada, "Non-Insured Health Benefits – Drug Benefits List January 2019" (February 2019), online: <https://www.canada.ca/en/Indigenous-services-canada/services/non-insured-health-benefits-first-nations-inuit/benefits-services-under-non-insured-health-benefits-program/drugs-pharmacy-benefits/drug-benefit-list.html>.

312 Indigenous Services Canada, "Appendix C – Palliative Care Formulary" (February 2019), online: <https://www.canada.ca/en/Indigenous-services-canada/services/non-insured-health-benefits-first-nations-inuit/benefits-services-under-non-insured-health-benefits-program/drugs-pharmacy-benefits/drug-benefit-list/app-c.html>.

313 LCO Engagement notes, Indigenous health care centre staff.

314 LCO Engagement notes, expert in Indigenous health policy.

*So if you're living in [a small remote First Nation] and you become ill, the clinic and services will support you for the first 12 months. After 12 months there is a regulation or policy that cuts you off. But you're not the provincial responsibility even though you 100% live and belong to the province. So you go to the [urban centre] where you don't know anyone, you don't know clinics, you don't have doctor, and you're walking around trying to figure you way around. It's a \$1000 to fly in your wife but no one will cover that either. It's a jurisdictional issue, plaguing and causing death for Indigenous people. And it's all about when the clock starts ticking.<sup>315</sup>*

*You have members who are registered, but there's no available housing on the reserve. So what happens is they want the care but can't access it because they are not part of the community and are excluded because it's so jurisdictional.<sup>316</sup>*

In the urban context, part of the response has been to create multi-use spaces that serve multiple interests and needs. But there are limits on how expansive these services are in comparison to the needs across the province:

*Make sure your work includes urban Indigenous. In the case [of this First Nation], it acknowledges urban Indigenous communities as political communities. But no one has really pushed for it, so we have created ourselves as a community articulating different spaces. It is different being a First Nation person experiencing racism as compared to an urban Indigenous person.<sup>317</sup>*

*Friendship Centres run health outreach programs. One is a very wide array of health services addressing chronic and palliative care as one continuum. Because the Centre is so actively engaged in care they are also the first place people go to for powers of attorneys, and are also acting as advocates. But there's not enough services that are culturally appropriate and culturally safe, there are only ten AHACs in Ontario. It serves as a touch point, to connect, sometimes they can be only aboriginal organization that's there. It's seen as safe place in many urban settings... People are looking to the reserve but they don't have end of life care, so they will go to urban care setting. That's the idea. If someone can't get care in their community they go to urban centre where the Friendship Centre acts as the support and will even support the family.<sup>318</sup>*

The jurisdictional challenges create particularly difficult decisions for rural and remote communities. In these communities it is often the case that more complex care is unavailable on reserve, with the consequence that travel to provincial facilities and larger urban areas is necessary. As one person put it:

*From the Western perspective you must come to [the urban centre] to get treatment. It will prolong your life but disconnect you from family. The choice is that you can either live longer but in a miserable racist marginalized area. Or die sooner, surrounded by community. But you can't have both.<sup>319</sup>*

315 LCO Engagement notes, Indigenous health care centre staff.

316 LCO Engagement notes, expert in Indigenous health policy.

317 LCO Engagement notes, expert in Indigenous health policy. See the discussion about the *Misquadis* precedent above.

318 LCO Engagement notes, expert in Indigenous health policy.

319 LCO Engagement notes, Indigenous health care centre staff.

*When you were doing the piece, make sure the importance of family comes up. In Toronto there is such a large transitory [Indigenous] population receiving health care that there is no effective way to assist the family, like having supportive places for family to stay. It extends beyond the parents or the sister, it can often be ten or more people surrounding a person. But right now trying to make this space, and sacrificing to come into the city is a big burden. It should be easier to be with someone who is going through that [end-of-life] journey.<sup>320</sup>*

*Discharges from the hospital to homes in this community is awful. The wider hospital system around us [off reserve] has little understanding of this community; people get discharged into this community with no supports. One hospital called the home care team on a Friday afternoon and said they're going to discharge – but homecare said there's no services. Hospital said we're gonna do it at noon the next day anyway. The patient condition meant she didn't even meet the discharge targets and thresholds.<sup>323</sup>*

The provision of palliative care is particularly frustrated by the disconnect between rural and remote service from more urban settings.

Policy and legislative gaps like these can result in concerning medical transfers done without due care and consideration.

*We have a small hospital and people can feel trapped in there because they can't get the care they need. One member of the community palliative outreach team had to go into the hospital to provide the care even though technically she didn't have privileges to do so.<sup>321</sup>*

*What happens when hospital wants to discharge someone? They'll try and find another Indigenous person to act as an escort since they otherwise can't discharge the sick patient. "I have to get is an escort" is what they say. One example they sent my uncle on a bus right after his surgery.<sup>324</sup>*

*When people do go out of community, they go to the emergency room at the hospital but there are problems there that frustrate palliative care. One big issue we're hearing is that one of the outreach patients went to the ER and was denied care because "you were palliative" and "we don't have any options to transfer palliative to ALC beds." In another case we were told that "the patient is dying but her pain has gone back to baseline so we can discharge her." They're not looking at the patient needs holistically, just looking at it like a transaction. And the stats will show that they didn't extend the length of stay for that issues and got more discharges and so they don't get fined for the ER waiting.<sup>322</sup>*

*What happens in my community in a medical emergency is that someone takes the patient in their own vehicle, they don't have 911. So you have to call the ambulance and find out if it is coming from Sudbury or Timmins. Then you try to meet them halfway and pull off to the side of the highway and transfer the patient into ambulance that way. But it's hard. For long stretches there's no cell phone coverage on the highway.<sup>325</sup>*

320 LCO Engagement notes, expert in Indigenous health policy.

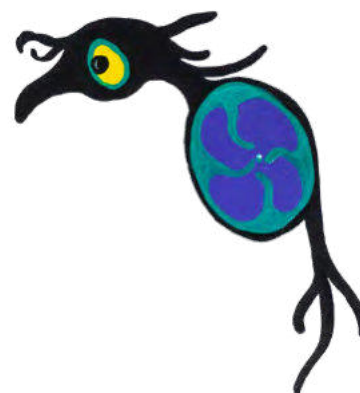
321 LCO Engagement notes, Indigenous physician.

322 LCO Engagement notes, Indigenous physician.

323 LCO Engagement notes, Indigenous physician.

324 LCO Engagement notes, Indigenous community member.

325 LCO Engagement notes, Indigenous health care centre staff.



These kinds of problems are compounded by the reality that minimal basic infrastructure is lacking. Such a lack can force or coerce certain decisions against the wishes, value or beliefs of the patient or their family and community. For instance, a lack of housing, access to clean water, or limited local primary health care can frustrate all attempted to receive home care. It also triggers a cascade of other jurisdictional issues, such as costs associated with travel; applications for special funding programs; travel for family members and escorts; frustrations in supporting substitute decision making and the participation of wider community members; interruptions to continuity of care; the need for policies and funding for respite leave and opportunities to visit the home community from time to time; and care in an urban setting that may not be culturally accommodating or safe.

*We had dietitian who fell apart in my office. She came in and was upset with people being non-compliant with her recommendations. But as she was going to go through their cabinets to show them how to change things she realized they had no food. All this time she's been saying "have a salad" and saying they're non-compliant but she was talking about food they didn't have.<sup>326</sup>*

*Some of these people don't have clean water for dialysis. It forces them to leave their community and never go back. This is province of Ontario.<sup>327</sup>*

These kinds of problems also manifest out of the legislative and policy structures governing long-term care homes. On accessing long-term care from a rural remote community to a larger urban centre one participant noted:

*The Western application process is very long, our patients start it or don't want to deal with it. As a matter of law reform, I don't think there is reference to the **Long-Term Care Homes Act**. There should be Indigenous mention [for priority admission].<sup>328</sup>*

*The long-term care home said "If you leave you can't come back. So you can't get leave or respite care to visit your community. I heard that Ottawa has funding for people in Nunavut to go back and forth like that. That would help here too.<sup>329</sup>*

*Indigenous people are 50% of the population in this area but I can count the handful of Indigenous clients I serve in LTC.<sup>330</sup>*

Concerns over the tension in self-determination and jurisdiction is particularly pronounced for organizations serving urban indigenous in relation to the introduction of Ontario Bill 74, *The People's Health Care Act*. The Act dissolves most LHINs, folds agencies including Cancer Care Ontario back into the Ministry of Health, and aims to reorganize the health care system into several dozen self-organized "Ontario Health Teams" comprising an internal mix of acute, long-term, and home care services to support around 300,000 people each. As mentioned earlier, Indigenous organizations like the Chiefs of Ontario took specific issue with the lack of consultation around this legislation.

326 LCO Engagement notes, Indigenous health care centre staff.

327 LCO Engagement notes, Indigenous health care centre staff.

328 LCO Engagement notes, Indigenous health care centre staff.

329 LCO Engagement notes, Indigenous health care centre staff.

330 LCO Engagement notes, Indigenous physician.

Some Indigenous service providers felt that their autonomy is likely to be impacted as a result:

*We don't know where we'll end up. But if you don't have a partnership you can bet you'll get a partner. In [our urban community] we're the only off-reserve organization that serves the Métis population. But we don't have Chiefs on our board, or the Friendship Centre. We feel like we're kind of sitting waiting to get shot like a sitting duck.*<sup>331</sup>

A key reason for ongoing deficiencies in Indigenous health care service delivery stems from uncertainty and confusion over competing federal and provincial jurisdictions. The case of Jordan River Anderson – whose situation led to the development of Jordan's Principle – underscores the consequences of these jurisdictional disputes. Jordan, a special needs Norway House Cree Nation child whose family lived on-reserve but was receiving medical care off-reserve, was forced to stay in a hospital for an extra two years because the governments of Canada and Manitoba could not agree on responsibility over payment for in-home services as the recommended option for Jordan by doctors.<sup>332</sup> The tragic result of this impasse, as the Assembly of First Nations (AFN) put it, was that Jordan died at age 5 “without ever having spent a single night in a family home.”<sup>333</sup>

Out of this situation, Jordan's Principle was developed to ensure that First Nations children should not experience service denials, delays, or disruptions due to jurisdictional disputes over the provision or payment of services.<sup>334</sup> The TRC made this their Call to Action #3 for all levels of government,<sup>335</sup> and more recently the Canadian Human Rights Tribunal (CHRT) further validated Jordan's Principle to apply to *all* First Nations children, not just those with multiple disabilities.<sup>336</sup>

In line with the CHRT's ruling, the Ontario Legislative Assembly enacted the *Child, Youth and Family Services Act, 2017 (CYFSA)* on April 30, 2018. The preamble of the *CYFSA* acknowledges the applicability of Jordan's Principle to all Indigenous children regardless of status, and section 339 (1) provides for the Lieutenant Governor-in-Council to make regulations to prescribe and govern a dispute resolution mechanism in accordance with Jordan's Principle to resolve any jurisdictional disputes.<sup>337</sup>

The AFN noted in its February 2017 *Health Transformation Agenda* that what occurred to Jordan also “profoundly impacts adults. There are many cases of First Nations adults who are denied services from provincial ministries and the [FNIHB], both claiming the other is responsible while the same service would be provided to a non-First Nations person without hesitation.”<sup>338</sup> As such, the AFN noted that among First Nations communities there is a general lack of consensus over whether health care should be provincial or federal jurisdiction. For instance, many First Nations “see the Treaty relationship as one with the Crown, as represented by the federal government,” and thus see health care as the responsibility of solely the federal government.<sup>339</sup>

331 LCO Engagement notes, Indigenous health care centre staff.

332 Assembly of First Nations, “The First Nations Health Transformation Agenda” (February 2017) at 27-28, online: [https://www.afn.ca/uploads/files/fnhta\\_final.pdf](https://www.afn.ca/uploads/files/fnhta_final.pdf) (AFN 2017).

333 AFN 2017 at 28.

334 AFN 2017 at 28.

335 TRC Calls to Action, Call 3.

336 *First Nations Child and Family Caring Society of Canada v Attorney General of Canada* (2016 CHRT 2) (FNCFCS) at para 382.

337 *Child, Youth and Family Services Act, 2017* (SO 2017, c 14, sched 1) at s.339 (CYFSA).

338 AFN 2017 at 31.

339 AFN 2017 at 31.

Alternatively, some First Nations prefer to partner with the provinces and the federal government. For its part, given this diversity of views, the AFN declined to recommend a consensus organizational preference, but did call on all levels of government to “immediately commit to a patient-first principle, in line with Jordan’s Principle, for all First Nations people, regardless of age or residency.”<sup>340</sup>

In its April 2016 *Daniels*<sup>341</sup> decision, the Supreme Court of Canada (SCC) ruled that Métis and non-status First Nations are considered “Indians” under s 91(24) of the *Constitution Act, 1867*, which states that the federal government has exclusive authority over “Indians and Lands reserved for Indians.”<sup>342</sup> In her reasons, Justice Abella noted that although this classification would “not create a duty to legislate” on the federal government, it would still end a “jurisdictional tug-of-war” and “legislative vacuum” stemming from “the fact that neither [the provincial nor federal] government has acknowledged constitutional responsibility” over both groups.<sup>343</sup>

*Daniels* does not mean that Métis and non-status First Nations were accordingly registered under the *Indian Act*. However, the clarification of jurisdictional authority could have an ancillary effect on the health care of both groups. It is important to note that the TRC’s Call to Action #20 calls on the federal government to “recognize, respect, and address the distinct

health needs of Métis, Inuit, and off-reserve Aboriginal peoples” in order to “address the jurisdictional disputes concerning Aboriginal people who do not reside on reserves.”<sup>344</sup> As Dalhousie law professor Constance MacIntosh has noted, while through the federal First Nations and Inuit Health Branch (FNIHB) a range of health benefits are available to status First Nations and recognized Inuit, similar benefits are not readily available for Métis and non-status First Nations peoples “despite all Indigenous peoples experiencing significant health disparities.”<sup>345</sup> The decision in *Daniels*, MacIntosh further notes, is significant because it provides “a complete answer to the reason the federal government has always offered to justify its failure to act – which was that they lacked jurisdiction to do so. That answer can no longer be relied upon to excuse inaction.”<sup>346</sup>

For the 587,545 self-identifying Métis<sup>347</sup> (including 120,585 in Ontario)<sup>348</sup> and the 232,380 non-status First Nations<sup>349</sup> (including 85,475 in Ontario)<sup>350</sup> *Daniels* potentially opens up further avenues to increase access to federal health care services and reduce gaps in coverage resulting from jurisdictional disputes. It is important to note that in the *CYFSA*—Ontario’s child welfare legislation—the terms “Indian” and “native person” were replaced with “First Nations, Inuk or Métis child” to ensure that the statute applied to all Indigenous children in the province regardless of status under the *Indian Act*.

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340 AFN 2017 at 32.

341 *Daniels v Canada (Indian Affairs and Northern Development)*, 2016 SCC 12 (Daniels).

342 *Constitution Act* at s. 91(24).

343 *Daniels* at para 15.

344 TRC Calls to Action, Call 20.

345 Constance MacIntosh, “Indigenous Mental Health: Imagining A Future Where Action Follows Obligations and Promises” (2017) 54:3 *Alta L Rev* 589 at 602 (MacIntosh 2017).

346 MacIntosh 2017 at 605.

347 Statistics Canada, “Aboriginal Population Profile, 2016 Census” (18 July 2018), online: [https://www12.statcan.gc.ca/census-recensement/2016/dp-pd/abpopprof/details/page.cfm?Lang=E&Geo1=PR&Code1=01&Data=Count&SearchText=Canada&SearchType=Begins&B1=All&C1=All&SEX\\_ID=1&AGE\\_ID=1&RESGEO\\_ID=1](https://www12.statcan.gc.ca/census-recensement/2016/dp-pd/abpopprof/details/page.cfm?Lang=E&Geo1=PR&Code1=01&Data=Count&SearchText=Canada&SearchType=Begins&B1=All&C1=All&SEX_ID=1&AGE_ID=1&RESGEO_ID=1) (StatsCan 2016 Census).

348 Statistics Canada, “Focus on Geography Series, 2016 Census: Province of Ontario” (2017), online: <https://www12.statcan.gc.ca/census-recensement/2016/as-sa/fogs-spg/Facts-PR-Eng.cfm?TOPIC=9&LANG=Eng&GK=PR&GC=35> (StatsCan Geography 2017).

349 StatsCan 2016 Census.

350 StatsCan Geography 2017.

For its part, the OPCN *Delivery Framework* makes several recommendations specifically around the kinds of concerns raised with ambiguities and inconsistencies in legal jurisdiction. In particular, they call for the development of a:

Care Coordinator supporting the First Nations, Inuit, Métis, and urban Indigenous patient and their family/caregivers will be prepared and able to navigate jurisdictional issues to enable access to services and providers both within and outside of First Nations communities. The Care Coordinator must also be able to navigate disputes between provincial/territorial and federal programs to ensure coverage for appropriate health services for the First Nations, Inuit, Métis, and urban Indigenous patient. This may involve leveraging the expertise of existing First Nations, Inuit, Métis, and urban Indigenous coordination/navigation services, which may include:

- Indigenous Patient Navigators who support discharge planning, liaison between the provincial and federal home, community care, and social services programs, arrangement of language interpretation services, and connections with Indigenous Elders, Healers, or Knowledge Carriers;
- Local First Nations, Inuit, Métis, and urban Indigenous community health worker(s) and health directors;
- Federal Home and Community Care nurses who conduct case management in First Nations communities;
- Non-Insured Health Benefit Navigators;
- Community-based palliative care teams; and,
- First Nations, Inuit, Métis, and urban Indigenous Organizations (e.g., Indigenous Friendship Centres, Métis Nation of Ontario, Inuit Organizations and Aboriginal Health Access Centres).<sup>351</sup>

These recommendations were echoed by some of those the LCO spoke with:

*Biggest single issue for me is easy navigation, the system is so complex, people don't generally prepare for death, individual plus the family don't know where to go, what to do what is available, they rely on the person in front of them not always best knowledge. I would go further than public education though in favor of an Indigenous health advocate, having that knowledge on palliative but resources for Indigenous health advocate.*<sup>352</sup>

*2.5 years ago we did a mapping exercise of all the palliative care related services and referral patterns for nurses. They didn't talk at all about lodges, the role for the nurse practitioner, or the end-of-life pieces at all. We didn't land on standard process and for two years we're finding it hard to follow.*<sup>353</sup>

*We now have weekly meetings with the LHIN case manager. But even so we just found out that there are three different lists for access to palliative care that we never knew about for years. We have an MoU with [a hospice] now too.*<sup>354</sup>



<sup>351</sup> OPCN 2019, Recommendation 11.3, at 42.

<sup>352</sup> LCO Engagement notes, expert in Indigenous health policy.

<sup>353</sup> LCO Engagement notes, Indigenous health care centre staff.

<sup>354</sup> LCO Engagement notes, Indigenous health care centre staff.

In light of the above experience it is unsurprising to find that a Care Coordinator is unlikely to resolve all problems alone. The OPCN also specifically highlights the need for additional “implementation considerations” to address underlying systemic and structural sources of gaps and tensions related to jurisdictional issues. These include suggestions that:

- Federally and provincially provided health services for First Nations, Inuit, Métis, and urban Indigenous should complement and align with one another. Memorandums of Understanding (MOUs) between First Nations, Inuit, and Métis government, provincial health and social services ministries, and their federal counterparts should be established to improve effective use of resources.
- Federal funding should also be secured to increase the number of NIHB navigators who coordinate access to drugs and medical supplies in First Nations communities.
- Flexible funding through federal or provincial programs should be available for First Nations, Inuit, Métis, and urban Indigenous communities and organizations (e.g., Aboriginal Health Access Centres, Friendship Centres, Métis Nation of Ontario) and for Healers, Elders, and Knowledge Carriers to build capacity in First Nations, Inuit, Métis, and urban Indigenous communities to provide culturally appropriate and safe palliative care. Supports should be in place to create physical space for cultural and spiritual practices/ ceremonies.
- The provincial government and LHINs should enable processes for dying at home in First Nations, Inuit, Métis, and urban Indigenous communities.<sup>355</sup>

The OFIFC has also highlighted how Canada’s current approach to developing a national Palliative Framework has so-far failed to adequately account specifically for urban indigenous groups in their plans. They recommend that such effort bring “urban Indigenous service organizations on as full and equal partners on palliative care teams for urban Indigenous people” and support “the training and capacity development of urban Indigenous service organizations.”<sup>356</sup>

Jurisdictional issues are also particularly challenging for Indigenous communities with territory abutting or crossing provincial, state, and international borders. The Akwesasne territory, for example, overlaps in jurisdiction with the provinces of Ontario and Quebec, the state of New York, and both the federal governments of Canada and the United States. It was shared that multiple jurisdictional authorities create barriers to access traditional practices through “rigid” standards and accreditation.<sup>357</sup> Akwesasne speakers rather expressed the role of trust and familiarity in the need to facilitate community-determined traditional practices. Facilitating access attempts to avoid incorporation and control of indigenous concepts by outside jurisdictions:

*It’s not equitable: in order to be a traditional person to get health care, you have to conform to health system of Ontario, Quebec, New York – to put themselves in that system, they are putting themselves in a foreign system and health cards, status cards are an affront to tradition/community/culture. Members of community don’t want to conform to something foreign – there’s a lack of recognition of differences. So much history that causes pain; Western/colonial laws supersedes community and culture.<sup>358</sup>*

355 OPCN 2019 at 44-45.

356 OFIFC 2019 at 9.

357 LCO Engagement notes, Indigenous health care centre staff.

358 LCO Engagement notes, Indigenous health care centre staff.



*We are not here to fit into Ontario system – it is clear and separate, but we need the support of the Ontario government to achieve that.*<sup>359</sup>

*[I am] forced to get professional accreditation in 2 jurisdictions and it is very difficult. So I can only work on a First Nations territory in Quebec, and not territory in Ontario.*<sup>360</sup>

Other First Nations in southern and western Ontario border Michigan or Wisconsin, and may be in easy driving distance of Indiana, Ohio, and Pennsylvania. Early in LCO's engagement we heard how many Indigenous groups find that cross-border rights are becoming increasingly difficult to freely enjoy. At the same time, there are reports that more band members in the United States are seeking healthcare in Canada due to increasingly restrictive US health care coverage.

In June 2016, the Standing Senate Committee on Aboriginal Peoples (APPA) released its report entitled *Border Crossing Issues and the Jay Treaty*<sup>361</sup> as a means to “encourage the federal government and First Nations to work together to find practical solutions to the border crossing issue that will make it possible to maintain cultural and family ties between First Nations communities in Canada and Native American communities in the United States.”<sup>362</sup>

To complete this report, the APPA invited engagement with a range of officials from the former Indigenous and Northern Affairs Canada (INAC), the Canada Border Services Agency (CBSA), the Mohawks of the Akwesasne, and the AFN. As the Report notes, some First Nations in Canada believe that they should have the right to freely cross the Canada-US border due to the *Treaty of Amity, Commerce and Navigation of 1794*—commonly referred to as the ‘Jay Treaty’—which was signed between the US and Great Britain to resolve issues following the American Revolutionary War. Article III of the Jay Treaty stipulates that First Nations may reside on and freely cross either side of the newly established border between British North America and the US.<sup>363</sup> However, as the SCC held in *Francis v The Queen*, “The *Jay Treaty* was not a Treaty of Peace and it is clear that in Canada such rights and privileges... are enforceable by the Courts only where the treaty has been implemented or sanctioned by legislation.”<sup>364</sup> As Parliament did not legislate the terms of the treaty the Supreme Court deemed it to have no practical application in Canada. Thus, First Nations entering Canada are subject to the same rules as all others. This also means that Native Americans in the US do not enjoy an automatic right to enter Canada.<sup>365</sup> First Nations born in Canada, however, are entitled to freely enter the US “for the purpose of employment, study, retirement, investing, and/or immigration.”<sup>366</sup> In order to qualify for these privileges, “eligible persons must provide evidence of their American Indian background at the port of entry...sufficient to show the bearer is at least 50% of the American Indian race.”<sup>367</sup>

359 LCO Engagement notes, Indigenous health care centre staff.

360 LCO Engagement notes, Indigenous health care centre staff.

361 Senate of Canada, *Border Crossing Issues and the Jay Treaty: Report of the Standing Senate Committee on Aboriginal Peoples* (June 2016) (Chair: Hon Lillian Eva Dyck) (Jay Treaty 2016).

362 Jay Treaty 2016 at 7.

363 Jay Treaty 2016 at 7.

364 *Francis v The Queen*, [1956] SCR 618, 3 DLR (2d) 641 at para 5.

365 Jay Treaty 2016 at 8.

366 U.S. Embassy and Consulates in Canada, “First Nations and Native Americans” (date accessed June 2019), online: <https://ca.usembassy.gov/visas/first-nations-and-native-americans/>.

367 U.S. Embassy and Consulates in Canada, “First Nations and Native Americans” (date accessed June 2019), online: <https://ca.usembassy.gov/visas/first-nations-and-native-americans/>.

Given the difficulties associated with bordering crossing for some Indigenous communities, like the Akwesasne First Nation, the APPA recommended that INAC “explore further solutions” to address this situation.<sup>368</sup>

In December 2016, the federal Minister of Indigenous and Northern Affairs responded by appointing Fred Caron CD, QC as the Minister’s Special Representative to engage with affected Indigenous communities and offer possible solutions to challenges faced. Caron observed that “there was a fairly common sentiment expressed by First Nations people...that First Nations’ status was an advantage in entering the United States, but a disadvantage when re-entering Canada.”<sup>369</sup> Given the US’ continued recognition of the Jay Treaty, Caron notes, when entering the US, “First Nations people from Canada were not treated as immigrants for the purposes of work, school and some federal public benefits.”<sup>370</sup>

Pursuant to section 19 of the *Immigration and Refugee Protection Act* (IRPA), Canadian citizens and Indigenous Peoples registered under the *Indian Act* have “the right to enter and remain in Canada,”<sup>371</sup> with the same rights applying to permanent residents of Canada.<sup>372</sup> All other travelers who enter Canada—including Native Americans not registered under the *Indian Act*—are essentially considered ‘foreign nationals’ (immigrants) subject to admissibility requirements under Canadian immigration law.<sup>373</sup> Consequently, as Caron put it, “Many of the First Nations people I met with consider their treatment by the US in this regard to be more consistent with their understanding of their inherent

rights as First Nations.”<sup>374</sup> Altogether, Caron observed that the “current array of federal laws, regulations and policies” in Canada demonstrate a lack of recognition of inherent Indigenous rights, negatively affect familial and cultural ties, pose unnecessary barriers at ports of entry (through identity documents), allow for mistreatment from CBSA officers, restrict trade and the flow of personal goods, and allow for problematic locations of ports of entry, as in the case of the Akwesasne First Nation.<sup>375</sup>

In response to Caron’s report, the Government of Canada announced in December 2018 various measures to address these issues, including the addition of a machine-readable zone to the Secure Certificate of Indian Status (SCIS) card as a means to simplify the border crossing process for First Nations using the SCIS as a piece of identification at land and sea ports of entry between the US and Canada, recruitment of more Indigenous officers by the CBSA, more cultural training for CBSA staff, and improving outreach and cooperation by the CBSA with First Nation communities along the Canada-US border.<sup>376</sup>

None of these initiatives, it bears mentioning, directly considered the impact of freedom of movement on access to health care, or issues related to receiving continuing care in indigenous communities. Among those we talked to, experiences continue to be mixed in relation to the health care context.

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368 Jay Treaty 2016 at 12.

369 Fred Caron CD, QC, Minister’s Special Representative, “Report on First Nation border crossing issues” (August 2017), online: <https://www.aadnc-aandc.gc.ca/eng/1506622719017/1506622893512#sec3> (FN Border Crossing 2017).

370 FN Border Crossing 2017.

371 *Immigration and Refugee Protection Act*, SC 2001, c 27, s 19(1) (IRPA).

372 IRPA at s 19(2).

373 FN Border Crossing 2017.

374 FN Border Crossing 2017.

375 FN Border Crossing 2017.

376 Crown-Indigenous Relations and Northern Affairs Canada, “Canada implements measures to address Canada – United States border-crossing issues for First Nations” (December 2018), online: <https://www.canada.ca/en/crown-indigenous-relations-northern-affairs/news/2018/12/canada-implements-measures-to-address-canada-united-states-border-crossing-issues-for-first-nations.html>.

## Promising Directions for Future Health Law Reform

10. The province should clarify how Bill 74 and the formation of Ontario Health Teams will support the goals and commitments for Indigenous health care as set out in the TRC Calls to Action and UNDRIP, and particularly in relation to care in the last stages of life.
11. Discussion about law reform should not take place without considering basic infrastructure needed to implement any particular provisions, and this should involve both the provincial and federal governments as the latter primarily funds infrastructure on First Nation reserve lands.
12. Discussions about health care law should seek to realign federal and provincial palliative health care jurisdictional gaps and funding around the intersecting needs of all Indigenous communities, including on- and off-reserve First Nations, Inuit, Métis, and urban Indigenous communities, and particularly to support dying at home and on-reserve.
13. Provincial and federal engagement with urban Indigenous people should explore opportunities to better align on- and off-reserve services so that off-reserve services (which may also be funded federally) are able to meet the full set of traditional practices, laws, and customs.
14. Provincial and federal governments should review existing legislation to ensure Jordan's Principle applies to adults as well as children.
15. Provincial and federal governments should better coordinate on improving freedom of movement across international borders and such movement should be explored as an important aspect of health care and palliative and end-of-life care needs for Indigenous peoples.

Steps that the province of Ontario could take to further these goals:

- Expand Non-Insured Health Benefits (NIHB) programs to provide medicines for palliative care and include transportation benefits for patients and an escort.
- Fund First Nations organizations to build suitable and culturally appropriate hospices.
- Clarify a strategy within the formation of Ontario Health Teams to support the development of Indigenous Health Teams.
- Commence development of a “health infrastructure” strategy to identify and begin addressing the systemic lack of health resources in Indigenous communities.



## E. Facilitating Traditional Practices Governing Death in the Home and Natural Burials

As discussed in LCO's LSL Discussion Paper, the province of Ontario is making major efforts to promote care at home, and part of this is planning for death at home. That study found numerous legislative and policy gaps that create inconsistencies and barriers for everyone in achieving these objectives. But as will become evident below, the several pieces of intersecting legislation and policies create particular challenges for Indigenous communities. To begin, it merits providing a brief outline of the legislative and policy scheme.

Among the pieces of legislation having an impact are the *Coroner's Act*, the *Vital Statistics Act*, and the *Funeral, Burial and Cremation Services Act*.

The coroner or police must be notified under the *Coroners Act* where there is reason to believe that the death was suspicious or requires investigation (e.g., violence, negligence, suddenly and unexpectedly). As mentioned above, family and friends are otherwise not required to initiate a police or coroner's investigation when a natural death is expected.

The *Vital Statistics Act* (VSA) creates some restrictions on how the deceased can be treated. For instance, burial, cremation, funeral services and transportation outside a municipality cannot take place until required documentation has been obtained. In Ontario, death certificates can only be issued by one of three professionals: a physician, nurse practitioner or the coroner. This can again introduce delay. If the deceased remains within the municipality the VSA does not require a death certificate before transporting the deceased. However, the LCO heard that funeral services commonly insist on first obtaining a death certificate, often out of fears for liability where the death was actually suspicious.

There are two improvised tools that have been created in Ontario to aid expected deaths at home: Expected Death in the Home (EDITH) Protocols and Guidelines from the Office of the Chief Coroner for Ontario.

EDITH protocols evolved as a grassroots response to a perceived gap and are overwhelmingly favored in the palliative care community across Ontario. The protocols provide funeral homes with the reassurance that they may transport the deceased after death upon a so-called "pronouncement" of death, before a death certificate is provided, thus reducing delay. There is not a single EDITH Protocol for Ontario, and several jurisdictions (including Toronto) do not use them. Several EDITH Protocols have been developed, and they share many common features:

- Enable nurses, beyond nurse practitioners, to make a pronouncement and states that a physician will provide the funeral home with a death certificate within 24 hours.
- Confirm that CPR is not included in the treatment plan, including use of the DNR Confirmation form.
- Identifies the primary health care provider and an alternate with their afterhours contact information, along with information on alternative courses of action should problems arise.

The Guidelines of the Office of the Chief Coroner simplify the process of obtaining a death certificate in cases where they have already been called-in, and help employees to manage the situation in a timely manner and to avoid investigatory proceedings.

Other jurisdictions, like British Columbia, take a more proactive approach. A provincial protocol and companion legislation allows the patient's physician to complete a form and send it to the funeral home before the death, along with an agreement to complete the death certificate within 48 hours after the death (and thus goes further than Ontario's DNR Confirmation form). In these situations, family and friends can themselves contact the funeral home directly to arrange for transportation without the involvement of a health care provider at all.

The LCO was also told that it can be difficult for family and friends to arrange for a physician or nurse practitioner to visit their home to issue a death certificate, as many professionals are not habituated to making home visits after hours or on weekends.

Consequently, family and friends may end up contacting the police or coroner’s office in the event of either a natural or MAID death to reduce any delay associated with the burdensome process or arranging the attendance of a physician or nurse practitioner.

Similarly, multi-jurisdictional territories must deal with differing laws governing pronouncement of death and burial location:

*Coroner issue: If you die in Quebec, only a doctor can pronounce dead; in Ontario, nurses have that power. They have one doctor who must attend to all deaths on Quebec side of Akwesasne.<sup>377</sup>*

*If he’s from our community -- if he wasn’t from their community, he’s taken to Ottawa to bury in a grave someplace – we ensure he’s buried here. Again, we need a PGT person in community – more efficient / get guidance sooner.<sup>378</sup>*

Finally, the ***Funeral, Burial and Cremation Services Act*** acts to regulate the funerary industry, cemetery operators, transfer services for the deceased, and sets standards related to burial, scattering of ashes, and cremation.

This legislative scheme doesn’t always work well for Indigenous communities.

Some participants spoke to the challenge of managing deaths at home:

*All these days that it takes to actually get someone buried isn’t traditional for us. It’s supposed to happen quickly but the Western system and process is so slow.<sup>379</sup>*

*What are the legislation around home deaths? Things don’t work as well as they can. Fortunately we have a local person who can act as coroner, but there was no one available early in the morning to pronounce the death to move the body. Because there was no DNR in place the coroner had to be called. The body stayed there until 8PM in the evening and local police had to support the family.<sup>380</sup>*

*What other policies does coroner have for other religious accommodations that they’re not undertaking for Indigenous communities? Frontline providers aren’t asking questions planning before hand, a body is removed in a certain way they weren’t able to do their ceremony, someone did go in and bathe before they wanted to do the ceremony. Simple question wasn’t asked in advance, you have family that is left without that closure.<sup>381</sup>*

*When you have a death in the family it’s the outside clan “the opposite side” that’s supposed to help because the family itself is clouded in darkness. We need to have a real discussion about a real traditional burial without funeral homes.<sup>382</sup>*

377 LCO Engagement notes, Indigenous health care centre staff.

378 LCO Engagement notes, Indigenous health care centre staff.

379 LCO Engagement notes, Indigenous Elder.

380 LCO Engagement notes, Indigenous physician.

381 LCO Engagement notes, Indigenous physician.

382 LCO Engagement notes, Indigenous community Healing Person.

Some participants emphasized how legislation and costs are silencing traditional belief and practices in how to manage the body after passing.

*Do we do that, cremate, embalm? We talked a little bit about traumatic deaths and suicide and how that affects our journey when we pass. There was a comment that people are doing cremation because it's cheaper. We don't really conduct traditional burials. We felt we needed to inform the community and ask how cost is affecting what our beliefs are. We invited another elder to participate too and it was a good exchange... people don't have a connection to traditional ways.<sup>383</sup>*

*In another situation the person passed at home and the family didn't want embalming because it's not our way. So they took the body in a pickup to a graveyard, using dry ice. It was 24 hours later. The gravedigger asked for death certificates but there wasn't one, and so we had to chase one down. Later we were told "you aren't supposed to do that" but that's what we used to do a long time ago too. The surviving partner later debriefed with us and said she wished that there wasn't all that jurisdictional stuff to deal with.<sup>384</sup>*

*We had family members come from up north, she passed and we did the bathing here, and the hospital staff were freaking out, you can't take her out until those people who are waiting come in, and they say you can't touch the body that way, that's their wish when the family is finished then you can take her. The staff nurse on ICU, no one has ever done that, you never give them opportunity, it's beautiful to give them that opportunity. You can expect them to ask the questions but they don't.<sup>385</sup>*

*Natural burials in Indigenous communities (where the tradition is to "plant the person in the ground") are illegal because they contradict with the environmental, health and safety. Use of Traditional laws for cremation is illegal, Western funerary practices are presumed by default at funeral homes. Body is only "respected and treated properly" if the family fights for it. How do (or don't) EDITH protocols and newly introduced expedited review procedures of the Coroner consider Indigenous practices?<sup>386</sup>*

*Funeral home managers are also withholding death certificates pending payment, even though the Department of Indian Affairs has a payment protocol.<sup>387</sup>*

*When people die, they request them to go there, carry the nation fire, repent to the creator, then ask for forgiveness, then the 10-day feast...but it is not respected in the laws...INAC ignores it.<sup>388</sup>*

383 LCO Engagement notes, Indigenous community Healing Person.

384 LCO Engagement notes, Indigenous community Healing Person.

385 LCO Engagement notes, Indigenous community Healing Person.

386 LCO Engagement notes, Indigenous Elder.

387 LCO Engagement notes, Indigenous physician.

388 LCO Engagement notes, Indigenous community Healing Person.

The sentiment expressed was that preservation of traditional ways only managed to exist as a “workaround” existing legislation:

*We haven't really had a traditional burial in the last 100 years. The family is supposed to meet and the woman are supposed to hire people to conduct the ceremony: create the casket, dress the body, make the clothing, a meal to travel with. Its more where the funeral homes are involved, the coroners, etc. But we still do follow all the old protocols even though there's a funeral director, the certificates, etc.<sup>389</sup>*

*We were thinking about having our own event and bringing in traditional knowledge keepers to share information with the community about these practices. People are burying loved ones in their backyard. If they're embalmed and not encased, it leaks out into the land and the streams. Want people to be able to make informed decisions.<sup>390</sup>*

People also expressed the need for local, in-community resources to make things run well under existing legislation, otherwise breaches are inevitable.

*Just this year a local doctor was made a coroner and that helps us a lot.<sup>391</sup>*

But this isn't always feasible:

*Especially in northern Ontario and the unavailability of a coroner there can be concern for how the deaths are characterized i.e., natural causes or violent death.<sup>392</sup>*

Similarly, traditional outdoor fires may conflict with rural and urban environmental law on private or public lands, which only some municipalities accommodate by adopting by-laws.



389 LCO Engagement notes, Indigenous community Healing Person.

390 LCO Engagement notes, Indigenous health care centre staff.

391 LCO Engagement notes, Indigenous health care centre staff.

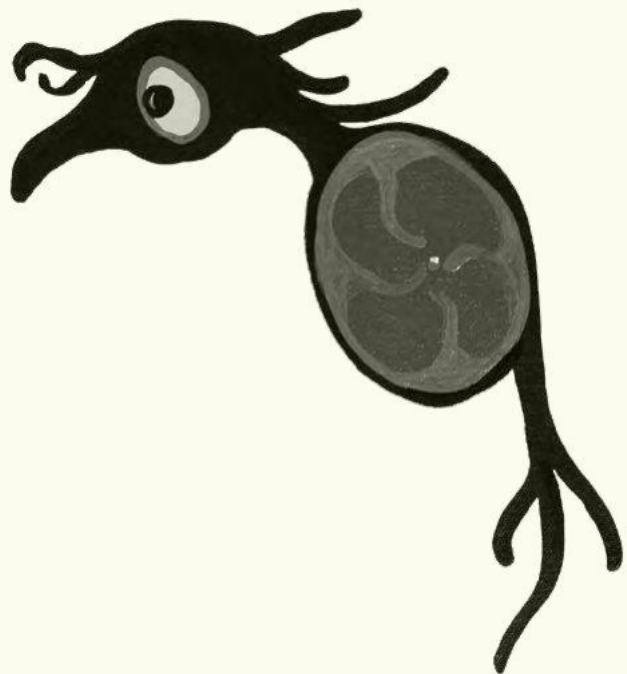
392 LCO Engagement notes, Indigenous physician.

## Promising Directions for Future Law Reform

16. Explore ways to make requirements under the Coroner's Act, Vital Statistics Act and other related legislation accommodating of Indigenous traditional laws and practices at the time of death. This should include finding proactive or more responsive ways to certify expected deaths and take into consideration the role of traditional healers along with the limited rural, remote, or on-reserve availability of medical professionals qualified to declare death. This should also involve the federal government where there are relevant *Indian Act* provisions addressing the consequences of death, and where federal operational and policy issues relate to accessing remote reserves and communities.
17. Explore ways to make requirements and prohibitions under the *Funeral, Burial and Cremation Services Act*, environmental legislation including the *Environmental Protection Act* and *Environmental Assessment Act*, as well as any relevant municipal bylaws, support the diversity of practices in Indigenous communities respecting the handling of the deceased such as natural burials, and other community practices like ceremonial fires.
18. Explore ways to support traditional cremation practices by reviewing requirements under the *Funeral, Burial and Cremation Services Act*.
19. Explore better ways to manage bureaucratic requirements so the grieving family isn't burdened at the time of death and during other recognized cultural periods.

Steps that the province of Ontario could take to further these goals:

- Establish a broad working group of Indigenous communities, the province, and municipalities to review Indigenous funerary and burial practices. Information gathered from this study would then be used to support a range of meaningful and substantive reform initiatives above.
- Direct the Coroner of Ontario to undertake broad consultations with Indigenous communities on a series of policy reforms to better support Indigenous funerary and burial practices, province-wide coverage, expanded local partnerships, etc.
- Support calls from groups including the GIPPEC conference and OPCN recommendations to expand patient navigation and linguistic / cultural translation services in healthcare and deathcare to ensure equitable access and services.





## F. Measuring Health Care Performance with Indigenous Practices and Values

Different views of quality of service and measuring and allocating resources were a common theme across nearly all engagement discussion. Such measures can result from a mix of legislated, regulated, and policy enactments designed to shape effective health care outcomes, with the goal of making an efficient allocation of resources while doing so. However, what constitutes an “effective outcome” for some is the exact opposite for others, and this includes many examples directly and indirectly impacting Indigenous people in Ontario.

With the recent Bill 74 reorganization of Ontario’s health care system around Ontario Health Teams, and plans to integrate agencies mandated to measure, report and integrate palliative and end-of-life care systems including Health Quality Ontario and Cancer Care Ontario back into the Ministry of Health, it appears as timely as ever to highlight promising directions towards the self-determined creation of “Indigenous health care indicators.”

Doing so would also help Indigenous service providers to tell their own story in ways that will contribute to positive legal changes. Right now, this lack of legitimacy means “We have no autonomy other than that what we create behind the door. The most impactful issue are those criteria for eligibility to access and barriers. That’s what’s going to give us more autonomous delivery to our community.”<sup>393</sup> But the stakes are high: “As a service provider we then risk losing our funding if we’re not following the regulations; so we feel trapped between the two worlds.”

There were many examples given that would support a dramatically improved approach. Each of these constitute “promising directions for future law reform conversations.”

- **Transactional measures don’t reflect meaningful health care work in the Indigenous context.** For many Indigenous service providers, an overriding principle is to provide holistic care. Holistic care promotes effective outcomes but these aren’t measured or reported on.<sup>394</sup> “Tracking beds, people services, no continuity of services, or in terms of what happens to those peoples, they can’t justify there are services being provided. It puts us in the position of trying to justify making recommendations to do the work that has to be done. There has to be a different way of considering data. I’m having to say, “we will never meet your target.” I don’t feel bad about it. These LIHN or ministry target. In some we exceed triple, I don’t really care, it’s quality over anything. To the extent these things aren’t measured it perpetuates racism.”<sup>395</sup>
- **There should be measurement specifically of “culturally relevant indicators.”** “We tell stories, support reasons, and share success stories. In one case this approach meant a rape victim counsellor wouldn’t see anyone else. She should have seen four patients in that block of time, but she is supporting that person in the crisis. Culturally relevant indicators would catch the reflection of what we do. What do we need to do is capture our story.”<sup>396</sup>
- **OHIP billing codes don’t facilitate holistic care in line with Indigenous expectations.** “If someone wants to tell me a story I need to sit and listen to that story. It should be bundled care. The money should follow the patients. Its otherwise too instrumental and rigid. The billing codes don’t let me provide that holistic service that is time consuming but important, and part of wellness.”<sup>397</sup>

393 LCO Engagement notes, Indigenous health care centre staff.

394 OFIC 2019.

395 LCO Engagement notes, Indigenous health care centre staff.

396 LCO Engagement notes, Indigenous health care centre staff.

397 LCO Engagement notes, Indigenous physician.

- **Billing in multi-jurisdictional settings creates perverse choices for patients.** “They [Akwasasne] have an agreement with Quebec regarding funding (co-pay); but if a person goes to Cornwall for services, OHIP will pay Ontario doctors \$65, Quebec health will only pay \$40. The patient pays the difference. Ontario rates cause hardship for Akwasasne: they withdraw services and require clients to pay up front.”<sup>398</sup>
- **Initiatives to reduce emergency department admissions and wait times create perverse incentives that don’t reflect the reality of Indigenous experiences.** Indigenous communities need to transfer patients to the ER for out-of-community services simply because there is no alternative. Ontario initiatives that only measure transactional outcomes don’t meet Indigenous needs or dignity. They also create perverse incentives that tie funding and performance awards to efforts that directly oppose Indigenous approaches, such as further segmenting care.

As one participant put it: “In another case we were told that “the patient is dying but her pain has gone back to baseline so we can discharge her.” They’re not looking at the patient needs holistically, just looking at it like a transaction. And the stats will show that they didn’t extend the length of stay for that issues and got more discharges and so they don’t get fined for the ER waiting.”<sup>399</sup>

- **Holistic care includes the needs of family and community cultural practices and traditions.** “When someone has completed their cycle of life we will go to the visitation or funeral that doesn’t happen in health care, we continue and still supporting their family, helping through grief, they may need navigator for another system”<sup>400</sup>

- **Perverse incentives prompt health care providers to more quickly characterize Indigenous patients as “non-compliant.”** This, unfortunately, can have an effect on the funding of organizations like AHACs. But the statistic doesn’t tell the whole story or do so fairly. For example, some spoke of some specialists interpreting a “no-show” as “non-compliant” and then blackballing an entire referral organization like an AHAC because of losing out on billing for that time. As a major referral pathway, this can make it impossible for Indigenous patients to get a referral to a specialist. Similarly, cultural factors may not be taken into account in how an issue is communicated to Indigenous patients. For example, some Indigenous health providers report that a lot of clinicians are quite to write “non-compliant” when the patient is apparently unable to follow instructions. But to what extent did the health care provider speak to the patient in a way they could understand? As several participants commented:

*I’m a huge proponent for traditional medicine, particularly for mental health care. But if you’ve been diagnosed with schizophrenia you are only offered to “take your medications” and the pros and cons of that without exploring traditional approaches. When it goes to people’s beliefs you want to respect that.*<sup>401</sup>

*When you’re with a patient you should never use the word “non-compliant.” If you are working together you’re not meeting the target you need to change how you approach care with them, use their story and their relationship, use what is important to them to help achieve their goal, taking same approach in their health journey.*<sup>402</sup>

398 LCO Engagement notes, Indigenous health care centre staff.

399 LCO Engagement notes, Indigenous health care centre staff.

400 LCO Engagement notes, Indigenous health care centre staff.

401 LCO Engagement notes, Indigenous health care centre staff.

402 LCO Engagement notes, Indigenous health care centre staff.

*We had a practitioner characterize a patient as non-compliant because she would refer the patient to physio but they wouldn't go. But it was because they can't afford the physio, not because they're not compliant. They just don't have the money.*<sup>403</sup>

- **Better measures would be more respectful of Indigenous traditions.** “Two row Wampum and having our own path: the two paths shouldn't interfere with each other: Western and Indigenous. They should be distinct. That's regarded as part of a Great Law. Better tracking could prompt recognition of our own statistics and member needs. It would bring down all those barriers to having our own hospice.”<sup>404</sup>

*It is the Great Law of Peace: peace, respectful, caring, accountability, responsibility, balance... this Health Department uses strength-based approach, we use talents of everyone to be collectively better.*<sup>405</sup>

The promising directions suggested here reflect similar recommendations made by the OFIFC in response to the federal development of a Palliative Care Framework for Canada. There the OFIFC cited the need for the following:

- Urban Indigenous service communities and organizations be actively involved in all Indigenous palliative care research, including the development of an evidence base for non-medical aspects of palliative care.
- Urban Indigenous communities and organizations be actively involved in the development of precise Indigenous indicators related to palliative care.
- All data collection be made relevant to the urban Indigenous population.



403 LCO Engagement notes, Indigenous health care centre staff.

404 LCO Engagement notes, Indigenous physician.

405 LCO Engagement notes, Indigenous health care centre staff.

## Promising Directions for Future Law Reform

20. Indigenous communities should be directly involved in the development of health care measures, indicators and reporting to better ensure these reflect Indigenous approaches to health and wellness as well as to take lived experience into account so measures do not penalize Indigenous communities.
21. Transactional performance and efficiency measures and OHIP billing codes don't reflect meaningful health care work in the Indigenous context. For many Indigenous service providers, an overriding principle is to provide holistic care. Holistic care promotes effective outcomes but these aren't measured or reported on. Holistic care includes family and community cultural practices that are not measured or reported on.
22. Explore the development of Indigenous "culturally relevant indicators" to change the way health care services are defined, measured and billed, and to create a way to measure the performance of the system in achieving culturally competent service by staff and the creation of culturally safe spaces. This should be done with both the provincial and federal government particularly where health care professionals may be employed by federal ministries or agencies or by First Nation Band Councils.
23. Measures designed to monitor and create incentives for reducing ER wait times discriminate against Indigenous communities who routinely need to transfer patients to the ER for out-of-community services. These measures should take such circumstances into account.
24. Criteria for determining patients as "non-compliant" or "no shows" should be reviewed to take Indigenous experiences into account, and to ensure there are no perverse incentives to quickly dismiss patients with this status.



## G. Supporting Indigenous Health Professionals in Community

The serious mental and moral stress that health care providers experience when working continuously with persons nearing death was a recurring theme during the LCO's preliminary consultations. The LCO's LSL project reviewed current legislative responses designed to support health care providers in general. Palliative and end-of-life care specifically may take place in several different workplaces and require support for several different people. This can include the role of a health care provider in supporting patients, SDMs, family and friends, while also working in different contexts including health care facilities, in home and community settings, in other government facilities (jails, youth detention centre, etc.), all while having professional obligations defined by organizations such as regulatory colleges.

The existing literature confirms that persons working as health care providers experience a higher incidence of stress and "burnout" than employees in other sectors. Specific stressors for palliative care providers include "absorption of negative emotional responses, breaking bad news, challenges to personal beliefs, coping with inability to cure, immersion in emotional clashes, poorly defined roles, recurrent exposure to death, working in an area of uncertainty, patient suffering, and secondary trauma."<sup>406</sup> Nurses and PSWs in long-term care homes also face stressors connected to caring for persons with declining health and dementia, and to their regular exposure to death. At the same time, there is a lack of systemic education and supports for providers' mental wellness.

In addition to these, several issues the LCO's LSL consultation specifically heard about clustered around workplace-related experiences like compassion fatigue; trauma and PTSD; workplace safety, training and education (on issues other than medical content); workplace wellness and employee assistance programs

(EAPs); and the limited supports defined in legislation.

Several pieces of legislation touch on these issues but are all limited in various ways, and don't reflect the specific needs of practitioners working predominantly in palliative and end-of-life care. For example:

- The **Occupational Health and Safety Act** protects employees from health and safety "hazards" in the workplace that could potentially result in harm, but doesn't specifically include workplace environments that may negatively impact employees' mental health (such as exposure to frequent death).
- The **Workplace Safety and Insurance Act** was amended in 2016 to better account for the prevalence of post-traumatic stress disorder (PTSD) in first responders, including paramedics and emergency medical attendants. The Workplace Safety and Insurance Board (WSIB) must also now presume that PTSD is work-related, unless the contrary is proven. Still, many health care providers are not covered who might experience workplace distress, such as nurses, social workers and PSWs.
- There may also arise **competing rights** between health care providers and their patients. For instance, a patient of a particular creed may request that care be provided by professional of particular sex or sexual orientation (raising potential discrimination issues), or request that a service provider remove footwear in the home or certain areas of the home (conflicting with health and safety requirements).

LCO research also found considerable legislative movement on some of these issues over the last several years. For instance, no fewer than five pieces of provincial legislation were introduced between 2016 and 2018 making amendments to the WSIA and OHSIA. Generally these amendments were in the nature of expanding workplace injury benefits to

406 LSL Discussion Paper 2017 at 131, citing Rebecca C. Hill, Martin Dempster, Michael Donnelly and others, "Improving the wellbeing of staff who work in palliative care settings: A systematic review of psychosocial interventions" (2016) *Palliative Medicine* 1, 2, online: <http://pmj.sagepub.com/content/early/2016/03/09/0269216316637237.full.pdf+html>.

groups including first responders with PTSD arising out of and in the course of their employment<sup>407</sup>, and later for work-related chronic and mental stress.<sup>408</sup> This however invited considerable critique as setting a WSIB policy standard for “chronic mental stress” higher than that of traumatic mental stress claims, with the consequence that very few workers have been able to access the benefit.<sup>409</sup> The overall impression we got in our consultations was that accessing such supports was sufficiently onerous, unpredictable and limited as to not be worth the trouble of trying to get.

Later amendments were enacted that extended the presumptive chronic mental health stress coverage to front-line nurses in addition to first responders,<sup>410</sup> as well as extending the presumptive categories of coverage for traumatic mental stress to members of the College of Nurses of Ontario who provide direct patient care.<sup>411</sup>

Despite these moves, Ontario continues to lag behind other jurisdictions in Canada. For instance, Manitoba’s legislative framework presumes that PTSD results from workplace trauma but does not limit coverage to specific occupations, rather applying to all workers covered by the province’s Workers Compensation Board,<sup>412</sup> as the nature of the workplace environment is the focus more than the nature of the occupation itself. As the (then) Premier of Manitoba Greg Selinger put it, “It makes sense to deal with [PTSD] regardless of

what occupation you have, what job you have. If you’re experiencing the issue, it impairs your ability to do your job.”<sup>413</sup>

At the federal level, the House of Commons Standing Committee on Public Safety and National Security endorsed recommendations in October 2016 to create a clear and expanded definition of a broader and more inclusive category of “Operational Stress Injuries” that accounts for PTSD and other mental health problems such as depression or substance suffered in relation to work. On June 21, 2018, Bill C-211, the Federal Framework on Post-Traumatic Stress Disorder Act received Royal Assent.<sup>414</sup> Pursuant to this Bill, the respective federal Ministers of Health, Public Safety and Emergency Preparedness, Veterans Affairs, and National Defence must, within one calendar year of this Act coming into force, convene a national conference to develop a federal framework on PTSD with various stakeholders, including representatives from provincial and territorial government responsible for health as well as from the medical community and patients’ groups.<sup>415</sup> The purpose of this framework is to improve the tracking of the incidence rate and associate economic and social costs of PTSD; establish guidelines on diagnosing, treating, and managing PTSD; share best practices across Canada on treating and managing PTSD; and create educational materials on PTSD for use by public health care providers to enhance public awareness.

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407 Bill 163, *An Act to amend the Workplace Safety and Insurance Act, 1997 and the Ministry of Labour Act with respect to posttraumatic stress disorder* (1st Sess, 41st Parl, 2016) (assented to 6 April 2016), SO 2016, C4), online: [http://www.ontla.on.ca/web/bills/bills\\_detail.do?locale=en&Intranet=&BillID=3713](http://www.ontla.on.ca/web/bills/bills_detail.do?locale=en&Intranet=&BillID=3713) (Bill 163 2016).

408 Bill 127, *Stronger, Healthier Ontario Act (Budget Measures), 2017* (SO 2017, c 8, sched. 33) (Bill 127 2017).

409 Toronto Star, “Workers’ compensation board denies over 90 per cent of chronic mental stress claims, audit shows” (December 4, 2018), online: <https://www.thestar.com/news/gta/2018/12/04/workers-compensation-board-denies-over-90-per-cent-of-chronic-mental-stress-claims-audit-shows.html>.

410 Bill 177, *Stronger, Fairer Ontario Act (Budget Measures), 2017* (SO 2017, c 34, sched. 45), online: <https://www.ontario.ca/laws/statute/s17034>.

411 Bill 31, *Plan for Care and Opportunity Act (Budget Measures), 2018* (SO 2018, c 8, sched. 37), online: <https://www.ola.org/en/legislative-business/bills/parliament-41/session-3/bill-31>.

412 *The Workers Compensation Act*, SM 2015, c 13, CCSM c W200, s 4(5.8).

413 Quoted in The Globe and Mail, “Manitoba to ease PTSD claims for all covered workers” (8 June 2015), online: <http://www.theglobeandmail.com/news/national/manitoba-to-ease-ptsd-claims-for-all-covered-workers/article24869020/>.

414 *Federal Framework on Post-Traumatic Stress Disorder Act*, SC 2018, c 13.

415 *Federal Framework on Post-Traumatic Stress Disorder Act*, SC 2018, c 13, s 3. This conference was held in Ottawa on April 9 and 10, 2019.

Notwithstanding recent developments in this area, there is ongoing uncertainty about the constitutional application of provincial labour laws, such as Ontario's *Employment Standards Act*, to First Nation Band Council employees in certain circumstances, including those pertaining to employees involved in end of life health care services. The Federal Court of Appeal's recent decision in *Picard v Quebec*,<sup>416</sup> for instance, found in favour of federal labour jurisdiction in the particular policing context at issue in the case. This may be distinguished from opposite rulings in other contexts, particularly the decision of the SCC in *NIL/TU,O Child and Family Services Society v. B.C. Government and Service Employees' Union*<sup>417</sup> and the federal court of Canada in *Nishnawbe-Aski Police Service Board v. Public Service Alliance of Canada*.<sup>418</sup>

Jurisdictional uncertainty underscores the importance and emphasis the LCO heard in many engagements to better ensure an effective model for workplace wellness and supports for professionals working with Indigenous communities. This was related to the unique characteristics of working in Indigenous communities:

*If someone is unwell or dies it affects the whole community. The care workers have to support people but they need supports themselves and each other. You can feel the heaviness and its crippling to the work that needs to be done.*<sup>419</sup>

*There needs to be more support for the caregivers. The supports for them is minimal. Even in my agency (a LHIN) I see how nurses in the community don't get palliative pay and I can't ever get a straight answer on what benefits are supposed to be available.*<sup>420</sup>

*I'm one of only three nurses in this [on-reserve] community and one is on sick leave! Finding the balance between our nursing standards of practice and guidelines in a small community is very difficult when it comes to relationships and boundaries.*<sup>421</sup>

*Boundaries. Dr. [Name] lives on reserve and gets people showing up at her house in the middle of the night asking her to help. It places an undue burden on her. But in some way, we all do this locally as health care providers. None of which is reflected in any funding or supports. People will burn out. As I have burned out.*<sup>422</sup>

Many of the recommended approaches to addressing this were simply to better manage the workload, and to do so through policies that specifically support the hiring of Indigenous health care providers.

*I'd like to see improvement with an increase in staff. In a community membership around 12,000 people there are 17 PSWs and just two for palliative care. We miss a lot of the palliative clients as well. We don't have enough education for them to know our programs, or resources to provide them with services.*<sup>423</sup>

416 See *Picard v. Quebec* (2020 FCA 74).

417 See *NIL/TU,O Child and Family Services Society v. B.C. Government and Service Employees' Union* (2010 SCC 45) at para. 45

418 *Nishnawbe-Aski Police Service Board v. Public Service Alliance of Canada* (2015 FCA 211).

419 LCO Engagement notes, Indigenous health care centre staff.

420 LCO Engagement notes, Indigenous health care centre staff.

421 LCO Engagement notes, Indigenous health care centre staff.

422 LCO Engagement notes, Indigenous health care centre staff.

423 LCO Engagement notes, Indigenous health care centre staff.

*At the MOHLTC level there is a ton of policy and initiatives that come out and we're told that we were consulted but even if we were that's not reflected in the reports. There are 20 staff at Indigenous Cancer Control Unit as a branch of COO but only 3 staff are Indigenous. And fewer than 10 Indigenous people work at [our regional hospital]. As soon as you as a brown person want to get beyond the front line there is a glass ceiling. And there's a superficial service level consultation is not enough. We don't see ourselves anywhere in the health care system, either as a patient or a provider. We're locked out. And so that program causes pain and prevents change from happening at the top.<sup>424</sup>*

*Legislation lacks protecting caregivers (like medical transportation drivers, ambulance staff, and so on). New regulation in Ontario that allows for stress leave but where does that leave service delivery if everyone is on leave?<sup>425</sup>*

Band Council workplace and employment policies were also cited as being important legal instruments for improvement.

*We do this to ourselves too. So for example the Council policy says you can't take 10 days off when your parents die to do the 10 day feast. But the Council also ISN'T OURS – it is a colonialist structure. Families feel pulled in all directions: I need to do my job, help my family, support a sick loved one, etc. It means my clients need to be rescheduled. But the feedback from the community is that you are no longer available and they become upset. We don't have structures built within our services to allow the flexibility of staff to do their home roles and work roles. For example we have lots of nurses and PSWs, but only one speech pathologist. There's a dissonance in the community saying you aren't giving me what I need while I'm taking care of my own kids. And those two systems don't work together. How do we create a staffing service and employment policy that would facilitate this? It needs a truly Indigenous model.<sup>426</sup>*

*As a manager I want to ask "what has been done to make this person ready to work again so they won't be injured again?" I will ask them what they've done to prepare themselves but I get pushback because as employer I'm not supposed to ask the employee. Training for management like that is part of building capacity in the program. We're now getting training on identifying symptoms and signs to intervene earlier.<sup>427</sup>*



424 LCO Engagement notes, Indigenous health care centre staff.

425 LCO Engagement notes, Indigenous health care centre staff.

426 LCO Engagement notes, Indigenous health care centre staff.

427 LCO Engagement notes, Indigenous health care centre staff.



Traditional cultural practices are also seen as important to supporting workplace wellness for professionals:

*Several years ago we had 30 deaths in one month. And each death is a community event. But the staff tried to soldier on. We used the Four Strings ceremony. There were two days: one day of teaching, one day of ceremony. It lightened us a little bit. That was four years ago. And we just did it again at the end of January. Staff are now saying maybe we should do it once or twice a year. Or could we include our caregivers? We have a variety of faiths in this community, but we all have grief. We need to be responsive and keep the staff well too.<sup>428</sup>*

*Doing this in an Indigenous community is much more emotionally draining because you are working with your neighbours, friends, colleagues, etc. and the clients are friends, neighbours, etc. This week we lost five people in our community. Need to think of employee wellness as a lifecycle type thing because trauma is cumulative.<sup>429</sup>*

*Staff wellness and self-care is a real problem. We have a psycho-social bereavement counsellor, but she's already taken a leave after a year. And now we have no one. She ended up with a workload of over 100 clients.<sup>430</sup>*

The role and support provided by health professional regulators was also cited as an area for potential improvement. For example, some cited how the College of Physicians and Surgeons of Ontario “MD to MD consultation rule” is easily frustrated in rural and remote areas with few physicians. The result creates several undesirable effects, including instituting a gatekeeper function that impedes continuity of care; that fails to align with the reality of mobile services that may only be available one day a week and needs to see many patients at once; that “creates perverse incentive to go around or avoid the family doctor and instead go directly to a specialist – but that only helps if the person has a connection to the specialist in some regard;”<sup>431</sup> and that it diverts needed resources as “a case of duplication in the *Regulated Health Professionals Act* and in OHIP.”<sup>432</sup>

The structure of regulated health professionals was also criticized as constructing a sense of hierarchy that Indigenous communities eschew.

*Regulated health providers don't exist in community. The MD isn't any more important than a PSW. But that recognition isn't there for the PSW.<sup>433</sup>*

428 LCO Engagement notes, Indigenous health care centre staff.

429 LCO Engagement notes, Indigenous health care centre staff.

430 LCO Engagement notes, Indigenous health care centre staff.

431 LCO Engagement notes, Indigenous physician.

432 LCO Engagement notes, Indigenous physician.

433 LCO Engagement notes, Indigenous physician.



College standards were also cited as being oblivious of cultural dimensions:

*[Rules] around social media for example: it's harder for me to separate my personal and professional Facebook accounts; how you see and interact with the local community raises concerns and making sure to protect the client from harassment or the power imbalance (accepting gifts, giving people rides home, etc.). The College rules are oblivious to these cultural contexts.<sup>434</sup>*

*Go back to the colleges and have some way of reviewing the college guidelines from an Indigenous perspective by Indigenous providers and identify what makes us uncomfortable where we feel we're doing the right thing but not abiding strictly with those guidelines.<sup>435</sup>*

One concern, also mentioned earlier in this paper, is that merely inscribing Indigenous roles or inserting "cultural competence" into Western legislation can lead to undesirable outcomes.

*Birth Centres operates with an exception from the RHPA to conduct Indigenous traditional birth. But Indigenous midwives are paid different – they're not a "registered midwife" and the training and scope are slightly different, but they're doing the same job and not valued in the system. WTF?<sup>436</sup>*

*There is an example, in the regulation around midwives where aboriginal people are legislatively exempt from Ontario regulated midwives. It's a balance between recognition but not looking for regulation from Ontario government. What is needed is for the traditional health practices of people and communities to not harmonize with Western health care, but to exist as separate entities and see how they can harmonize together from that approach."<sup>437</sup>*

Despite these barriers and challenges to supporting professionals, meaningful change is possible. And where it works it works well:

*Sudbury [hospital] was the best: the management, partnering with Indigenous community, the delivery model, the way they transformed their board to be Indigenous, the strategy for their area, it all made as much as sense as possible. They treated Indigenous patients with some dignity and respect.<sup>438</sup>*

*How to build capacity and those supports? Look to the TRC recommendations: increase the number of Indigenous health care providers, yes, but also figure out how to support them through the western education system, and get through to the other side and still be able to connect with and serve their community.<sup>439</sup>*

434 LCO Engagement notes, Indigenous physician.

435 LCO Engagement notes, Indigenous physician.

436 LCO Engagement notes, Indigenous health care centre staff.

437 LCO Engagement notes, expert in Indigenous health policy.

438 LCO Engagement notes, Indigenous health care centre staff.

439 LCO Engagement notes, Indigenous health care centre staff.

## Promising Directions For Future Law Reform

25. Provincial and federal governments should work together with Indigenous communities and Indigenous health providers (in community or otherwise) to develop, implement and sustain health workplace support systems that account for the health care provider and health care teams as a member of those communities, participants in the cultural and grieving process, and often the only health providers available. This would include workplace wellness leave supports that account for entire community teams being on leave. It should also clarify federal, provincial and community jurisdiction over such supports and programs, with amendments to legislation as necessary, to ensure a responsive and sufficiently resourced system.
26. Health professional regulators should work together with Indigenous communities and Indigenous health providers (in community or otherwise) to develop, implement and sustain a distinct regulatory structure responsive to the needs of these providers and communities. This may include different expectations about relationships and boundaries within community, different systems for on-call and backfill roles, elimination of traditional Western conceptions of a professional hierarchy, and professional-to-professional consultation rules.
27. Health professional regulators should work together with government, educational institutions, Indigenous communities and Indigenous health providers (in community or otherwise) to develop, implement and sustain medical education that doesn't just include Indigenous students but respects their distinctive role and practice and educates others about this.
28. Health professional regulators should work together with governments and Indigenous communities and Indigenous health providers (in community or otherwise) to ensure that Indigenous health care providers – such as midwives – are recognized, compensated, and supported equally to that of their Western counterparts.



## H. Supporting Family and Caregiver Needs in Community

Caregivers play an indispensable role in Ontario's health care system. Exact numbers are hard to come by. But a study commissioned by the LCO estimated that 35,000 persons a year acted as end-of-life caregivers in a private home or long-term care facility.<sup>440</sup> 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:

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

The *Employment Standards Act, 2000* (ESA) 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. 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. For employees who are able to take leave, the ESA does not guarantee pay. Ontarians may be eligible for federal EI benefits, including the "Compassionate Care Benefit." But the LCO also heard that 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.

Another challenge is that leave is also limited by a maximum number of weeks within a period of time. A consequence of existing requirements is that caregivers may exhaust their entitlements or may not be able to take leave without interruptions. Continuity in leave for the actual time it takes to care for persons who are ill can therefore be difficult. 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.

Grief and bereavement care are understood as 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. The LCO heard that services are fragmented and psychological support has not been adequately integrated into palliative care. We were informed

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<sup>440</sup> This does not, however, count the number of caregivers assisting those with longer-term palliative or chronic conditions, which is certainly and vastly higher.

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. Ontario’s Fraser Report in 2016 echoes many of the issues the LCO is raising, remarking that “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.”<sup>441</sup>

In our general consultations the LCO heard of different approaches and proposals that would better assist caregivers and families to support someone in the last stages of life. 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” so that employment laws can properly take this role into account.

Many Indigenous communities understand the provision of care in community even more broadly than this. The provision of care – which would include palliative or end-of-life care – is understood as a model of reciprocity: community members are dedicated to supporting one another, and may take on whatever role is needed when, where and for as long as it is required. The caregivers may work alongside community health care providers. They may be the *de facto* health care provider where none are otherwise available, or only intermittently or on rotation. They may take the lead in providing traditional foods and medicines, and in overseeing customs and rituals. And this role isn’t necessarily limited to one’s immediate family, but to neighbouring families and clans too. It is a complex and varied role. Hospice Palliative Care Ontario, for instance, has created a First Nations Caregiver knowledge support website that includes no fewer than 15 different modules!<sup>442</sup>

Despite the evident importance of this role it is one which is often wholly excluded from consideration in Ontario legislation. This is a critical and harmful omission because of the innumerable potential complications it triggers and the barriers it creates. For instance, the provision of health care by community members could be characterized as violating legislated lines that demarcate health providers from all others. In this configuration only *legally* recognized health care professionals with certification and accreditation are authorized (and insured) to provide a service, but *community* members would not be. This may give rise to accusations of unauthorized practice of medicine or to liability or even criminal prosecution. The spectre of consequences like these surely have a chilling effect on the provision of community care and invite confusion and doubt, and which may arise even in communities where there are no formal health care services to rely on in the first place.

But that is only one of many examples where a commitment to fulfilling community and cultural roles to provide care are not acknowledged or anticipated by Ontario law. In another example, the priority in Indigenous communities for caregivers to take the lead in providing care is not reflected in employment standards legislation through recognized provisions for short, intermittent, or longer-term leave, along with guaranteed job protection, pay, and ready ease of quickly accessing such provisions. Where these kinds of concerns are generally reflected in current legislation they are without cultural or Indigenous specificity. Instead the criteria in fact, if not in theory, relies on the illness of the family member rather than on respecting and supporting the fulfillment of traditional community roles. Furthermore, in some Indigenous traditions, there is an expectation that other clans in the community will also help the family in need, particularly where the family of a deceased loved one is distraught. Again, there is no provision in legislation for this extended multi-family or community-oriented concept of care and reciprocity as a criterion for employment leave.

441 Ministry of Health and Long-Term Care, *Palliative and End-Of-Life Care Provincial Roundtable Report: A Report from Parliamentary Assistant John Fraser to the Minister of Health and Long-Term Care* (Ontario, 2016) at 17, online: [https://www.homecareontario.ca/docs/default-source/publications-mo/palliative\\_report.pdf?sfvrsn=6](https://www.homecareontario.ca/docs/default-source/publications-mo/palliative_report.pdf?sfvrsn=6) (Fraser Report 2016).

442 Hospice Palliative Care Ontario, *First Nations Caregiver Modules Website*, online: <http://caregiversupport.hpco.ca/ocpfn/>.

*When you have a death in the family it's the outside clan "the opposite side" that's supposed to help because the family itself is clouded in darkness.<sup>443</sup>*

This community expectation and role is also frustrated because it becomes a barrier to accessing health care services. For instance, one report comments that "If the palliative patient has existing family supports nearby, then they are denied services, as the families are expected to shoulder the burden, regardless of their situation."<sup>444</sup> In this situation, fulfilling community and cultural roles is effectively punished because it takes the Western view that such a role fills a gap in health care resourcing, rather than as something which is part of a more holistic model of care and which is otherwise important in and of itself for a whole host of valid cultural, spiritual, and traditional practices.

In another example, community youth are often involved in the provision of care too and may in fact be tasked with taking the lead for it. Some communities, for instance, have expanded this role for youth beyond a support role for immediate family, and instead to the wider community. In one community, for instance, youth aged 12-17 may enroll in a "death doula" program.<sup>445</sup>

Whatever the approach or role, these kinds of community and traditional obligations may put youth them in conflict with the law. Particularly requirements under an education act to attend school other than for specified criteria that don't take this kind of work into account. There is currently no provision in education law allowing for a range of short, intermittent, or longer-term leave from school to fulfill these community and cultural roles as needed.

This is a pitiable view of education. These youth may be out of school but are receiving an extraordinary rich education about their community, traditional laws, and cultural practices are around palliative and end-of-life care:

*Younger people are showing interest and want to get involved. I learned and studied with a Chief. Worked with the Elder for 10 years. Taught us the practices and protocols for these ceremonies. People in my own community told me there's no value but I thought there's gotta be. But there's not a lot of external supports for it. People are asking a lot of questions on traditional knowledge even through social media.<sup>446</sup>*

Many caregivers also face the prospect of travel. This may be to go into a larger urban centre to support a loved one receiving care in institutions that could include hospitals, long-term care, or respite care. It can also mean the family member themselves traveling back to community to support their loved ones there. Caregivers are also expected to provide for a wide array of services out of pocket, such as medical transfers, food, and their own accommodation if needed. The availability of support for these kinds of activities, we heard, is at best provisional and ad hoc, though usually non-existent.

443 LCO Engagement notes, Indigenous community Healing Person.

444 Southwest Ontario Aboriginal Health Access Centre, *Readiness Assessment Report: Indigenous Hospice Palliative Care Planning* (2017) at 3, online: <https://soahac.on.ca/wp-content/uploads/2015/01/Final-V7-SOAHAC-Palliative-Care-Report--July-31-16.pdf> (SOAHAC Palliative Report).

445 CBC News, "Indigenous death doula mentorship program aims to teach youth to help others through grief" (CBC News Manitoba, October 13, 2020, online: <https://www.cbc.ca/news/indigenous/death-doula-youth-program-1.5758005>).

446 LCO Engagement notes, Indigenous community Healing Person.

*You're going to come across a lot of time, families don't have financial resources, if it's taking time off to care for somebody coming into the city, there was pilot done with LIHN to support care giver, pocket money very free in the parameter, it was to support the caregiver themselves, knowing there was going to be pressure on the caregiver we couldn't determine what those pressures were, it's going to interfere with the care, having a fund to alleviate that pressure.<sup>447</sup>*

*All the stuff about transferring around and having to move to get services puts pressure on the family. They need financial support, they still have a home to maintain, and bills still have to be paid, ODSP, an source of income. We do touch base with them, and sometimes can get help from a clinic social worker to find providers for what they're looking for. But it's always luck of the draw for approval.<sup>448</sup>*

Among all caregivers there is also special consideration to be given for the role of Elders. Many we heard from spoke to the need to better support Elders in their role as caregivers, and in their role supporting the spiritual aspects and customs traditional to end-of-life care. We also heard that at present, these roles may fall to a community healer who is over-burdened and poorly supported. Both the Elder and community healer are hard pressed to support family caregivers and to pass along knowledge to them.

*Elders are not able to keep up with the needs.<sup>449</sup>*

*The person who is ill may be performing their final duties to visit with people. We do this at the hospitals often. There's no set time. You help when you are called to. Families are supposed to help – but its hard. The knowledge isn't there and the resources aren't there. Our view is to get a lot of people together to help but often [the community healer] feels like it falls to him to do alone.<sup>450</sup>*

A community healer may also encounter tension between their work and colonialist structures. For example, being employed through the Band Council may be seen as a colonialist structure, and which may adhere closely to the ESA. This can frustrate traditional roles which are flexible and provided when needed.

*I'm employed by the Council. Its really hard to tell if I'm on the job or not, and when I'm getting paid. It's a grey area that we haven't figured out how to fit in a western model of employment. Risk management for example: if [community healer] gets injured on the job when is he on the job? We're bound by the Employment Standards Act? This makes us a hand of the colonial system.<sup>451</sup>*

*We get funding for our services from the LHIN and from private donors. So if I have to go to the hospital and stay for a few hours it's fine, it's not rigid. The private donations allow us to provide service flexibly to meet the need of the patient in ways the system otherwise doesn't take into account. We're not trapped in the OHIP billing codes. We take as long as it needs and that's how it should work.<sup>452</sup>*

447 LCO Engagement notes, expert in Indigenous health policy.

448 LCO Engagement notes, Indigenous health care centre staff.

449 LCO Engagement notes, Indigenous community Healing Person.

450 LCO Engagement notes, Indigenous community Healing Person.

451 LCO Engagement notes, Indigenous community Healing Person.

452 LCO Engagement notes, Indigenous community Healing Person.

## Promising Directions For Future Law Reform

29. Explore ways to make legislation such as the Employment Standards Act and Education Act accommodate the role of Indigenous caregivers, particularly in supporting a community-oriented eligibility criteria and a low-threshold for immediate and flexible access and guaranteed protections for employment, income, out-of-pocket expenses. This should involve both the provincial and federal government given employment relationships of health care professionals to federal ministries or agencies or First Nation Band Councils and the jurisdictional questions around employment regulation.
30. Explore ways in which fulfilling the role of an Indigenous “caregiver” creates discriminatory eligibility barriers to services, supports, equipment, funding and programming and eliminate these barriers.
31. Explore ways to support Community Healers and Elders in their role in ways that are more flexible and supportive of their actual role and practices than current employment legislation contemplates. This should involve both the provincial and federal government given employment relationships of health care professionals to federal ministries or agencies or First Nation Band Councils and the jurisdictional questions around employment regulation.
32. Review professional regulatory legislation to better facilitate the role of a community caregiver as an active participant in the care team to limit the potential fear of recrimination, liability, minimization or exclusion.





## I. Access to Indigenous Hospices in Community

Nearly all persons who are dying will transition between care settings at some point in the course of their illness. But the illness trajectory for each person is unique. People may receive care in a variety of locations, including their own homes through community-based services, long-term care and retirement homes, hospital departments and in residential hospices.

A key component of end-of-life care involves eliminating emotional, social and physical distress for individuals and their supporters. However, inappropriate or poorly timed transitions increase distress for those who are already in an emotionally charged and difficult situation.

For Indigenous communities, there may be particularly compelling cultural and traditional reasons to want to spend the last stages of life in community. Yet many communities struggle to provide such services locally, and the problem is particularly pronounced in rural and remote communities.

This gives rise to concerns to receiving not only care at home, but for the provision of hospice services in the last days of life, and within community.

As we were told,

*When an Indigenous person says they want to “die at home” it may in fact mean the territory; this is in part why building a hospice makes so much sense. Birth and death are significant times when family is the medicine for that, but its also the time when those families and members are most likely to be taken out of their community to go to a health facility.<sup>453</sup>*

The reality can often be challenging to support the dying community member and their caregivers sensitively and holistically. Returning to community can often involve a maze of options and many closed doors:

*[Our community] was working to get palliative beds but I don’t know where that has landed. Mainstream hospices may not be where they want to be. If hospice isn’t right for them where do they want to go. Sometimes they can’t be at home, we don’t want people to pass in hospital because more expensive, but that’s where they end up. There is no alternative, we’re there doing visits in hospital, connecting with other [community and non-community] programs, piecemealing it together the best we can. But they often end-up in the ALC ward. Yes that’s right.<sup>454</sup>*

To explore these troubling gaps the Southwest Ontario Aboriginal Health Access Centre (SOAHAC) commissioned a report on access to hospice services in regional communities. Their *Readiness Assessment Report Indigenous Hospice Palliative Care Planning* found several key issues that needed addressing as pre-requisites to contemplating the establishment of a robust hospice care system in community. This includes:

- **Self-Determination:** “First and foremost, Indigenous people, First Nations communities and Aboriginal organizations in the South West LHIN solidly affirmed their readiness, capacity and desire for Indigenous palliative care services based on principles of self-determination, equity and social justice intended to improve quality of life for Indigenous people who are dying and their families.”

<sup>453</sup> LCO Engagement notes, Indigenous health care centre staff.

<sup>454</sup> LCO Engagement notes, Indigenous physician.

- **Access and Capacity:** “culturally safe palliative care services are not equally accessible to Indigenous peoples, particularly those that live on reserve. Research participants shared that the diagnostic process for palliative care is flawed, as it does not occur early enough and potential patients must satisfy rigid requirements in order to access care.”
- **Support:** “There is no education surrounding what to expect, who to call for support, or the inherent challenges in becoming a caregiver to a family member.[...] If the palliative patient has existing family supports nearby, then they are denied services, as the families are expected to shoulder the burden, regardless of their situation.”
- **Availability:** “It was evident throughout the interviews that Indigenous peoples are routinely denied access to palliative services if they do not have a working phone, internet or transportation to appointments... [and] are also denied services after 5PM if they live on reserve, while those that live in urban areas are able to access a caregiver at these times.”
- **Cultural Safety:** “This can take many forms, including a refusal to attend Indigenous palliative patients if they need care on reserve after 5 pm, ignorance of spiritual and cultural needs that are so important at the end of life, a lack of knowledge of Indigenous histories, rights and experiences, and well documented discrimination incidents... [this] has a detrimental effect on the quality of end of life care for Indigenous patients.”<sup>455</sup>

At present the need evidently greatly outstrips the ability of communities to support it. One report found that engagement participants “shared more than 40 examples of chronic patients who became palliative and wanted to die at home, however the South West CCAC acknowledged that they had only provided end of life care to 2 or 3 patients in the past two years.”<sup>456</sup>

The LCO acknowledges that explanations for these issues may not lie in the legal framework. Causes often relate mainly to health care challenges and resource constraints. For example, LCO commissioned research found that the vast majority of persons who die in hospital after a transfer from a private home had not been receiving home care services. And most of the persons who died in hospital upon a return admission in the last year of life had previously been discharged to home with no home care services.<sup>457</sup>

At the same time, however, the preceding content of this report details the innumerable examples of how existing legislation actively and structurally silences, sidelines, and sublimates nearly any attempt to live by the teachings of traditional Indigenous culture. So while resourcing is absolutely a consideration, the tremendous number of legal barriers that endlessly (and often needlessly) confound the provision of traditional Indigenous care certainly present a tremendous barrier to self-determination and the ability to effectively command any such resources provided.

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455 Southwest Ontario Aboriginal Health Access Centre (SOAHAC), *Readiness Assessment Report Indigenous Hospice Palliative Care Planning* (2015) at 3-4, online: <https://soahac.on.ca/wp-content/uploads/2015/01/Final-V7-SOAHAC-Palliative-Care-Report--July-31-16.pdf> (SOAHAC Palliative Report).

456 SOAHAC Palliative Report at 39.

457 See LCO Commissioned Paper, Dr. Donna Wilson & Dr. Stephen Birch, *Improved care setting transitions in the last year of life* (Toronto: 2016), online: <https://www.lco-cdo.org/wp-content/uploads/2010/10/Wilson%20and%20Birch%20Final%20Report%20%28LCO%20July%202016%29.pdf>.

The examples shares with the LCO in respect of hospice care evidence this ongoing concern. For instance, requests for resources may often be filtered through inappropriate criteria that takes a look at a given “catchment area” or population base to make broad determinations about what is appropriate and needed. This often misses the reality of what an Indigenous community actually is:

*But people come home from everywhere to die – so it’s not just about local population or in community population – our members are many and elsewhere but they want to come home to die.*<sup>458</sup>

*We don’t even know what our hospice would look like – would it be a traditional thing or something we do ourselves? We’ve been developing our own model of care but it isn’t being recognized. But we’re told there are already too many hospices in the area.*<sup>459</sup>

*There are multiple problems with using any other [out of community] hospices: 1) hospices are public and private funding so they take people who donate, not us; 2) a 25 minute drive is a big deal. And having to go off home territory is a big deal.*<sup>460</sup>

*I would prefer to just do palliative care in the community. I love my job at [this facility] because you can take the time to know the patient and meet the family and direct them to advance care and get them through those last days. But it doesn’t always work that way in the community either.*<sup>461</sup>

Some urban hospices do report some leniency and accommodation in meeting certain needs, such as allowing family members to stay on site, providing respite support, and in connecting out-of-town patients and family members to local urban Indigenous communities. For instance:

*We do have some beds set aside for respite. Here it is 12 beds for general admission and two beds for respite. The admission is two weeks long so we have to rotate the respite beds. Hotels would otherwise provide accommodation for family member who is dying, and that’s paid out of pocket by the family. We do have visitor policy, very similar to hospital, if we’re concerned they are at very end, people can come, people can stay, respectful of people on the unit, we allow people to stay over.*<sup>462</sup>

*No special services for Indigenous but connected to groups like [three named high-density urban area service provides]. We could do way more. But overall most clients with cultural needs can get connected to these groups within hours.*<sup>463</sup>

458 LCO Engagement notes, Indigenous community member.

459 LCO Engagement notes, Indigenous health care centre staff.

460 LCO Engagement notes, Indigenous health care centre staff.

461 LCO Engagement notes, Indigenous health care centre staff.

462 LCO Engagement notes, nurse providing care in community hospice.

463 LCO Engagement notes, nurse providing care in community hospice.

*We've cared for people who have lived through 60's scoop, living with physical and mental health issues... we do try to provide client centre care, need or want recognizing if we don't have that within our own team, we need to bring folks in, slowly become more acknowledging Indigenous clients need cultural component, you can't separate medicine from culture... it's us trying to find a way to mesh those, acknowledging self-determination.<sup>464</sup>*

Other facilities demonstrate less flexibility, often citing a restrictive interpretation of legislative provisions:

*Because we are hospital with a hospice, we have to follow health care act/hospital act. Can't use substance on the property. That gives rigidity to the care we provide. In a lot of ways we are square hold for round pegs. We try to embrace people from where they are, whether Indigenous or incarcerated but it can be intimidating.<sup>465</sup>*

*We're not allowed to smudge but we do have courtyard, when wanted to have [an event] we had two people lead us through smudging out there, we're not allowed to prevent from smudging. We did have people at the old building, we did have more flexibility, so it was allowed. We weren't hospital at that time. It would be good for our senior leadership, I don't want to put it on client to put that growth, people at bed side is not issue, but smudge is unique situation.<sup>466</sup>*

The SOAHAC report evidences the legal complexity in creating such programs even were resources to be provided. For instance, a primary recommendation they make is that:

*South West LHIN fund an Indigenous Hospice Palliative Care inter-professional team (collaborative) at SOAHAC to improve patient and system-level outcomes to be composed of: Registered Nurses, Nurse Practitioners, a Social Worker (with experience in grief and bereavement), a Mental Health Worker, a Traditional Healer, a Personal Support Workers (PSWs), Occupational Therapists/ Physiotherapists and Physicians.<sup>467</sup>*

But to achieve this is no small feat. As noted by the OPCN *Palliative Care Health Services Delivery Framework* such collaborative entities require “formalized jurisdictional collaborations across organizations and all level of governments and engage in seamless care coordination and management.”<sup>468</sup> Similarly both OPCN and SOAHAC recommend the establishment of “Indigenous Patient Navigators” to help “work with palliative clients and their families to introduce the Indigenous specific services, traditional practices as well as linkages to mainstream services that will bridge the gaps” and further that “all service providers working with Indigenous palliative clients and families be educated on the complexity of Indigenous Health issues, Indigenous rights to determination in health and be trained on Indigenous histories and cultural safety.”<sup>469</sup>

464 LCO Engagement notes, hospice social worker.

465 LCO Engagement notes, hospice social worker.

466 LCO Engagement notes, hospice social worker.

467 SOAHAC Palliative Report at 3-4.

468 OPCN 2019 at 41.

469 SOAHAC Palliative Report at 4; OPCN 2019 Recommendation 11.2 (the Indigenous Core Team), and 11.3 (Indigenous Patient Navigator).

But resolving these kinds of “formalized jurisdictional collaborations” could mean a lot of heavy legal lifting and include consideration of, among other things:

- Addressing complex legal and customary arrangements including insured and non-insured beneficiaries;
- Including the assistance of NIHB Navigator “to meet the unique transportation needs and provide seamless travel and supports (including family/ caregivers escort accommodation)” including fly-in communities and coordinated with First Nation, Inuit, and Métis in urban, suburban, and remote areas;<sup>470</sup>
- The assistance of NIHB Navigator to better coordinate universal “access to drugs and medical supplies” throughout the province;<sup>471</sup>
- Involving in these provincial teams the “Federal Home and Community Care nurses who conduct case management in First Nations communities;”<sup>472</sup>
- Partnering between provincial and federal governments in coordination with “with First Nations, Inuit, Métis and provincial/LHIN leaders to make 24/7 care available provincially;”<sup>473</sup>
- Partnering federal and provincial programs “should be available for First Nations, Inuit, Métis, and urban Indigenous communities and organizations... and for Healers, Elders, and Knowledge Carriers to build capacity in First Nations, Inuit, Métis, and urban Indigenous communities.”<sup>474</sup>



470 OPCN 2019 at Rec 11.9.

471 OPCN 2019 at 44.

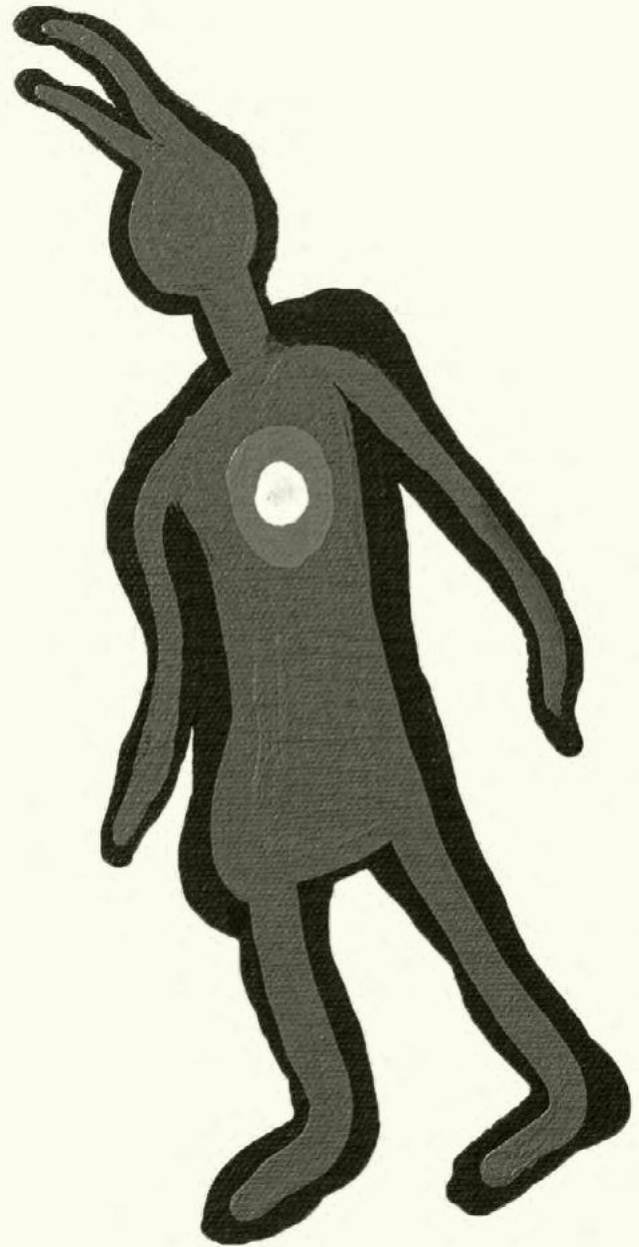
472 OPCN 2019 at 42.

473 OPCN 2019 at 44.

474 OPCN 2019 at 45.

## Promising Directions For Future Law Reform

33. Foster the development of self-determined in-community hospice and caregiver respite services through the continual elimination of legislated barriers to the provision of traditional Indigenous care. This should involve both the provincial and federal government to account for relevant federal legislative barriers and that many in-community services will be on reserve lands.
34. Establish distinct criteria for resourcing Indigenous hospice services that derive primary consideration from the needs of the community rather than using the lens of mainstream and regional availability of health care service delivery.
35. Commit the provincial and federal government to a timetable with regularly and continually released improvements that eliminate artificial jurisdictional distinctions that make holistic health service provision frustrated and nearly impossible to create.
36. Eliminate legislative confusion over issues like smudging and access to traditional medicine and foods particularly in the last stages of life for Indigenous community members who are forced to receive care in urban and suburban facilities far from home.





## **5** Summary List of Promising Directions for Future Reforms

## The Disparity between Indigenous Views and Health Care Terminology and Law

1. Indigenous communities should be engaged with both provincial and federal governments in defining supports in the later stages of life that are distinct from inherited terms like “palliative” and in which Indigenous services, programs and other practices are defined, organized and governed by traditional laws, culture and practices.
2. Provincial health care and intersecting legislation should be reviewed and made consistent with commitments required under UNDRIP and the TRC *Calls to Action* to ensure equitable and culturally safe access to health care everywhere in the province.
3. Look to Indigenous-led initiatives for guidance on recovering and prioritizing Indigenous traditions, laws, practices, culture and experiences in relation to palliative care, such as the OPCN’s Delivery Framework section on Palliative Care for First Nation, Inuit, Métis and urban Indigenous Communities and the Lakehead Improving End-of-Life Care in First Nations Communities.
4. Being open to the development of new performance measures, funding arrangements, OHIP billing codes, and recognition of traditional medicine, practices and knowledge in order to satisfy the needs of self-determined and self-defined programs and services.
6. Address racism and discrimination as barriers to care by ensuring a higher proportion of Indigenous health care staff, including those in positions of senior leadership.
7. Ontario Health Teams should regard compliance with Ontario’s Human Rights Code, the TRC Calls to Action, and UNDRIP as important as other health care standards and requirements.
8. Mandate a formal provincial wide policy to allow Indigenous traditional or spiritual services (ex. smudging, drumming) in health care institutions.
9. Explore the development of Indigenous “culturally relevant indicators” across both provincial and federal frameworks to change the way health care services are defined, measured and billed, and to create a way to measure the performance of the system in achieving culturally competent service by staff and the creation of culturally safe spaces.
10. Explore ways to make Indigenous Patient Navigators widely available, especially across provincial and federal programs and services, in off-reserve and urban areas, and include the Patient Navigators in Health Team planning and critical incident debriefs.
11. Explore ways in which health care service and professional regulators and oversight mechanisms, including adjudicative bodies, can work with Indigenous communities to develop meaningful, effective, and responsive complaints and investigation mechanisms. This should involve both the federal and provincial ministries or adjudicative bodies where there is shared jurisdiction, such as the Canadian Human Rights Tribunal, Federal Court, and where health care professionals may be employed by federal ministries or agencies or by First Nation Band Councils.

## Acknowledging Institutional Racism, Discrimination and Barriers to Cultural and Spiritual Practices

5. Address racism and discrimination as barriers to care by exploring legal and financial structures that can promote more autonomously delivered or self-determined Indigenous health care programs and services on behalf of both the provincial and federal governments.
12. Find ways to train health care professionals in both cultural competence and cultural safety, the later of which pays explicit attention to power relations between service providers and users. This should involve both provincial and federal governments as some health care professionals may be employed by federal ministries or agencies or by First Nation Band Councils.



## Reconceiving Health Care Consent, Capacity, and Substitute Decision Making

13. Review key provisions of the HCCA and SDA related to consent, capacity, best interest, ACP, “reasonable information” and substitute decision-making through Indigenous lenses. Consider alternate approaches that take into account more collective and community-based decision making, the time of reflection, Indigenous knowledge, and traditional laws for decision making.
14. Discuss a dispute resolution model for the kinds of decision-making issues arising under the HCCA and SDA that work for the local community.
15. Examine the role of the government institutions as “decision makers of last resort” in favor of local solutions and protocols and a role for the community.
16. Examine the role of formal and legislatively mandated legal instruments in both federal and provincial instances over Powers of Attorney for Personal Care, court-appointed guardians, and common law spouses in favor of traditional laws and approaches to these kinds of needs and relationships.
17. Expand the system-wide role for Indigenous Patient Navigators to assist as cultural translators and with all aspects of identifying care options, cultural and spiritual values and practices, conversations about consent and capacity, longer-term care planning around personal and community wishes, values and beliefs, etc. Consistent with shared responsibility for health care this should be explicitly coordinated between both the federal and provincial services, funding and programming.
18. Advance care planning designed to take into account the longer-term care planning around personal and community wishes, values and beliefs.

## The Impact of Jurisdiction on Jordan’s Principle and Equitable Access to Health Care

19. The province should clarify how Bill 74 and the formation of Ontario Health Teams will support the goals and commitments for Indigenous health care as set out in the TRC Calls to Action and UNDRIP, and particularly in relation to care in the last stages of life.
20. Discussion about law reform should not take place without considering basic infrastructure needed to implement any particular provisions, and this should involve both the provincial and federal governments as the latter primarily funds infrastructure on First Nation reserve lands.
21. Discussions about health care law should seek to realign federal and provincial palliative health care jurisdictional gaps and funding around the intersecting needs of all Indigenous communities, including on- and off-reserve First Nations, Inuit, Métis, and urban Indigenous communities, and particularly to support dying at home and on-reserve.
22. Provincial and federal engagement with urban Indigenous people should explore opportunities to better align on- and off-reserve services so that off-reserve services (which may also be funded federally) are able to meet the full set of traditional practices, laws, and customs.
23. Provincial and federal governments should review existing legislation to ensure Jordan’s Principle applies to adults as well as children.
24. Provincial and federal governments should better coordinate on improving freedom of movement across international borders and such movement should be explored as an important aspect of health care and palliative and end-of-life care needs for Indigenous peoples.

## Facilitating Traditional Practices Governing Death in the Home and Natural Burials

25. Explore ways to make requirements under the Coroner’s Act, Vital Statistics Act and other related legislation accommodating of Indigenous traditional laws and practices at the time of death. This should include finding proactive or more responsive ways to certify expected deaths, and take into consideration the role of traditional healers along with the limited rural, remote, or on-reserve availability of medical professionals qualified to declare death. This should also involve the federal government where there are relevant *Indian Act* provisions addressing the consequences of death, and where federal operational and policy issues relate to accessing remote reserves and communities.
26. Explore ways to make requirements and prohibitions under the *Funeral, Burial and Cremation Services Act*, environmental legislation including the *Environmental Protection Act* and *Environmental Assessment Act*, as well as any relevant municipal bylaws, support the diversity of practices in Indigenous communities respecting the handling of the deceased such as natural burials, and other community practices like ceremonial fires.
27. Explore ways to support traditional cremation practices by reviewing requirements under the *Funeral, Burial and Cremation Services Act*.
28. Explore better ways to manage bureaucratic requirements so the grieving family isn’t burdened at the time of death and during other recognized cultural periods.

## Measuring Health Care Performance with Indigenous Practices and Values

29. Indigenous communities should be directly involved in the development of health care measures, indicators and reporting to better ensure these reflect Indigenous approaches to health and wellness as well as to take lived experience into account so measures do not penalize Indigenous communities.
30. Transactional performance and efficiency measures and OHIP billing codes don’t reflect meaningful health care work in the Indigenous context. For many Indigenous service providers, an overriding principle is to provide holistic care. Holistic care promotes effective outcomes but these aren’t measured or reported on. Holistic care includes family and community cultural practices that are not measured or reported on.
31. Explore the development of Indigenous “culturally relevant indicators” to change the way health care services are defined, measured and billed, and to create a way to measure the performance of the system in achieving culturally competent service by staff and the creation of culturally safe spaces. This should be done with both the provincial and federal government particularly where health care professionals may be employed by federal ministries or agencies or by First Nation Band Councils.
32. Measures designed to monitor and create incentives for reducing ER wait times discriminate against Indigenous communities who routinely need to transfer patients to the ER for out-of-community services. These measures should take such circumstances into account.
33. Criteria for determining patients as “non-compliant” or “no shows” should be reviewed to take Indigenous experiences into account, and to ensure there are no perverse incentives to quickly dismiss patients with this status.

## Supporting Indigenous Health Professionals in Community

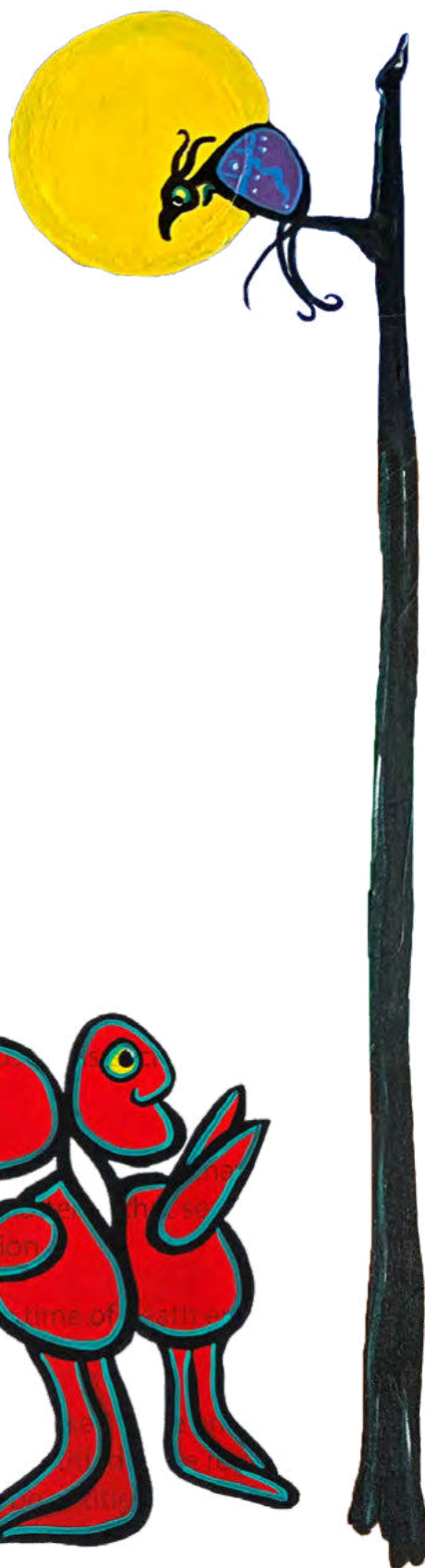
34. Provincial and federal governments should work together with Indigenous communities and Indigenous health providers (in community or otherwise) to develop, implement and sustain health workplace support systems that account for the health care provider and health care teams as a member of those communities, participants in the cultural and grieving process, and often the only health providers available. This would include workplace wellness leave supports that account for entire community teams being on leave. It should also clarify federal, provincial and community jurisdiction over such supports and programs, with amendments to legislation as necessary, to ensure a responsive and sufficiently resourced system.
35. Health professional regulators should work together with Indigenous communities and Indigenous health providers (in community or otherwise) to develop, implement and sustain a distinct regulatory structure responsive to the needs of these providers and communities. This may include different expectations about relationships and boundaries within community, different systems for on-call and backfill roles, elimination of traditional Western conceptions of a professional hierarchy, and professional-to-professional consultation rules.
36. Health professional regulators should work together with government, educational institutions, Indigenous communities and Indigenous health providers (in community or otherwise) to develop, implement and sustain medical education that doesn't just include Indigenous students but respects their distinctive role and practice and educates others about this.
37. Health professional regulators should work together with governments and Indigenous communities and Indigenous health providers (in community or otherwise) to ensure that Indigenous health care providers – such as midwives – are recognized, compensated, and supported equally to that of their Western counterparts.

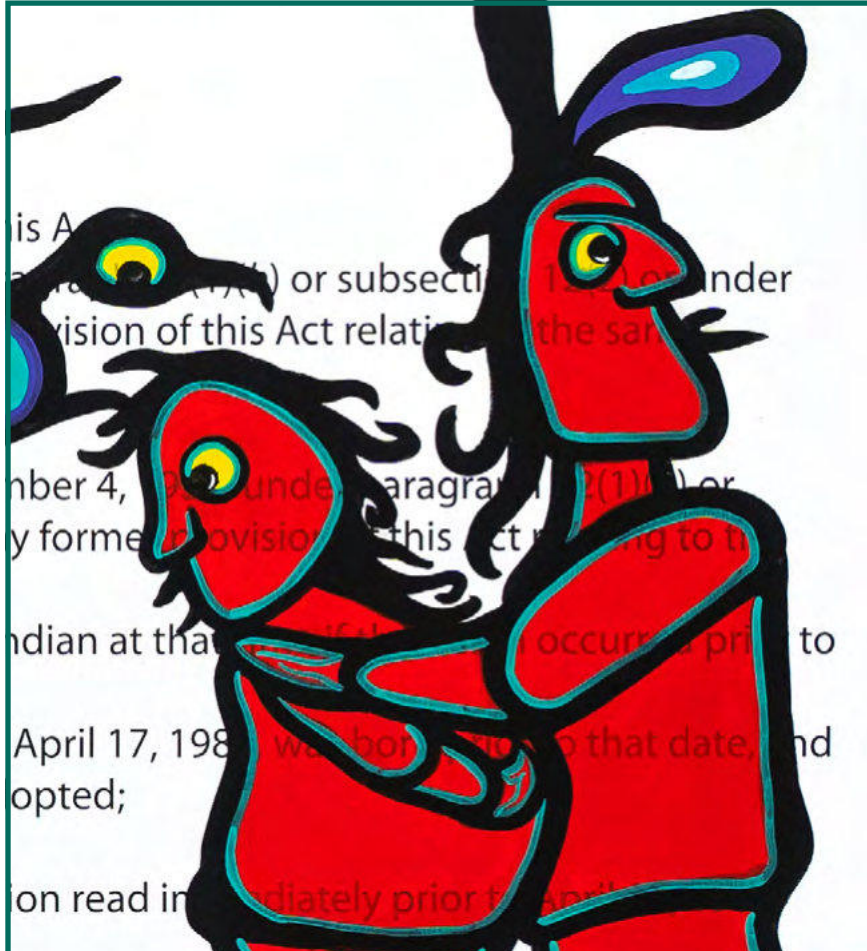
## Supporting Family and Caregiver Needs in Community

38. Explore ways to make legislation such as the Employment Standards Act and Education Act accommodate the role of Indigenous caregivers, particularly in supporting a community-oriented eligibility criteria and a low-threshold for immediate and flexible access and guaranteed protections for employment, income, out-of-pocket expenses. This should involve both the provincial and federal government given employment relationships of health care professionals to federal ministries or agencies or First Nation Band Councils and the jurisdictional questions around employment regulation.
39. Explore ways in which fulfilling the role of an Indigenous “caregiver” creates discriminatory eligibility barriers to services, supports, equipment, funding and programming and eliminate these barriers.
40. Explore ways to support Community Healers and Elders in their role in ways that are more flexible and supportive of their actual role and practices than current employment legislation contemplates. This should involve both the provincial and federal government given employment relationships of health care professionals to federal ministries or agencies or First Nation Band Councils and the jurisdictional questions around employment regulation.
41. Review professional regulatory legislation to better facilitate the role of a community caregiver as an active participant in the care team to limit the potential fear of recrimination, liability, minimization or exclusion.

## Access to Indigenous Hospices in Community

42. Foster the development of self-determined in-community hospice and caregiver respite services through the continual elimination of legislated barriers to the provision of traditional Indigenous care. This should involve both the provincial and federal government to account for relevant federal legislative barriers and that many in-community services will be on reserve lands.
43. Establish distinct criteria for resourcing Indigenous hospice services that derive primary consideration from the needs of the community rather than using the lens of mainstream and regional availability of health care service delivery.
44. Commit the provincial and federal government to a timetable with regularly and continually released improvements that eliminate artificial jurisdictional distinctions that make holistic health service provision frustrated and nearly impossible to create.
45. Eliminate legislative confusion over issues like smudging and access to traditional medicine and foods particularly in the last stages of life for Indigenous community members who are forced to receive care in urban and suburban facilities far from home.





## 6 About the LCO

## About the LCO

The LCO is Ontario's leading law reform agency. The LCO has a mandate to promote law reform, advance access to justice and stimulate public debate. The LCO fulfills this mandate through rigorous, evidence-based research; contemporary public policy techniques; and a commitment to public engagement. LCO reports provide independent, principles, and practical recommendations to contemporary legal policy issues.

A Board of Governors, representing a broad cross-section of leaders within Ontario's justice community, guides the LCO's work. Financial support is provided by the Law Foundation of Ontario, the Law Society of Ontario, Osgoode Hall Law School, and York University. The LCO is located at Osgoode Hall Law School in Toronto.

More information about the LCO is available at [www.lco-cdo.org](http://www.lco-cdo.org).

## What is the scope of the LCO's engagement?

The LCO acknowledges that our assessment of the issues and the scope of our engagement is limited by time, geography, and resources. The legal summaries provided later in this report reflect the experiences, concerns, and traditional laws, practices and culture explored through our engagement with Indigenous communities in Ontario.

We approached communities without preconditions to hear the concerns of greatest importance to them. These conversations resulted in the identification of nine themes around which this report and the LCO's reform recommendations revolve. These are:

- A) Aligning the Meaning of "Palliative" with Indigenous Approaches to Dying and Death
- B) Reconceiving Health Care Consent, Capacity, and Substitute Decision Making
- C) Acknowledging Institutional Racism, Discrimination and Barriers to Cultural and Spiritual Practices
- D) The Impact of Jurisdiction on Jordan's Principle and Equitable Access to Health Care
- E) Facilitating Traditional Practices Governing Death in the Home and Natural Burials
- F) Measuring Health Care Performance with Indigenous Practices and Values
- G) Supporting Indigenous Health Professionals in Community
- H) Supporting Family and Caregiver Needs in Community
- I) Access to Indigenous Hospices in Community

This report is also intended to be distinct from, but may be read alongside, the LCO's *Law in the Last Stages of Life: Final Report and Recommendations*.<sup>475</sup>

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475 LSL Final Report 2021. A survey of consultation and legal issues within the scope of that report is available in the *Last Stages of Life: Discussion Paper* (May 2017), online: <https://www.lco-cdo.org/wp-content/uploads/2018/06/LCO-Last-Stages-Issues-Backgrounders-1.pdf>. Extracts from that report which are more focused on Indigenous health and legal concerns are available as a standalone document, *Last Stages of Life: Discussion Paper Indigenous Extracts* (January 2019), online: <https://www.lco-cdo.org/wp-content/uploads/2020/04/LSL-Consult-Paper-Extracts-re-Indigenous-issues.pdf>.

That report makes a wide array of recommendations for improving the provision of palliative, end-of-life care, and medical assistance in dying in Ontario across 13 different categories of issues explored in that review, including how legislation shapes the experience of palliative and end-of-life care in areas including the following:

- 1) Consent and Advance Care Planning
- 2) Access for Communities with Unmet Needs
- 3) Public Health Approach to Palliative Care
- 4) Transition between Care Settings
- 5) Resolving Health Care Disputes
- 6) Withdrawing & Withholding Treatment
- 7) Supports for Professionals
- 8) Improving Professional Practice Tools
- 9) Palliative Sedation Therapy
- 10) Planned Deaths at Home
- 11) Caregiver & Family Needs
- 12) Medical Assistance in Dying
- 13) Cultural & Religious Needs

Some of the legislation or standards directly or indirectly influencing issues in this report and our companion report includes:

- 1) Health Care Consent Act
- 2) Substitute Decisions Act
- 3) Health Protection and Promotion Act
- 4) Long-term Care Homes Act
- 5) Ontario Human Rights Code
- 6) Accessibility for Ontarians with Disabilities Act
- 7) Regulated Health Professions Act
- 8) Employment Standard Act
- 9) Occupational Health and Safety Act
- 10) Coroner's Act
- 11) Professional and Institutional Regulatory standards, such as College policies and Institutional association guidelines

The discussion of these issues, and the recommendations made by the LCO in the *Law in the Last Stages of Life: Final Report* relate to this report in two important respects:

- 1) LCO's analysis and recommendations provide additional context for this report on Indigenous health law reform, but are not determinative of the issues raised here;
- 2) LCO's consultations with several different vulnerable and equity-seeking groups may help inform conversations about these groups in Indigenous communities, including those contending with HIV/AIDS, mental illness, disability, a history of incarceration, children receiving palliative care, and beliefs and practices rooted in a diversity of different cultures or spiritual groups.

Finally, the LCO also invited Indigenous engagement on the topic of medical assistance in dying (MAID). We heard that there is significant concern in many Indigenous communities over MAID. It raises many painful issues related to high rates of suicide in many Indigenous communities, and the many premature deaths related to substance use. Many communities are only in the earliest stages of discussing what MAID means to them, and none we spoke with had come to any consensus positions at the time. Furthermore, the LCO is aware that a conversation about mental health as a ground for seeking MAID is active and ongoing in all communities across Canada. This report and the engagements does not address the intersection of mental health and MAID.



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