



# INDIGENOUS END-OF-LIFE GUIDE TRAINING PROGRAM

2019/20–2023/24

EVALUATION REPORT



First Nations Health Authority  
Health through wellness



## "The Traveller" | Digital Illustration

Completed March 2022 | ne Secwépemc'ulucw | BC

### ABOUT THE PIECE

"The Traveller" was created by a family member of one of the Indigenous End-of-Life Guides. Use of the work by the program was generously gifted by the artist.

The initial inspiration for this piece originated from something a family member of mine told to me, a recollection on beginnings and ends and the journey in-between. Due to it being a sacred and personal story, I will not be writing it here. However, I took the piece beyond that story and added plenty of symbolism, all of which is completely up to individual interpretation. The water is still, and the eyes of the spirit guides are gentle, it is a welcoming and peaceful experience. The star, purposely shaped like a baby's fontanelle, is a bright window into that distant place where the Old Ones reside, ancient ancestors of the Spirit World. The pure, clear blue water reflects the Earth's perspective, the atmosphere, the distant star, the spiritual helpers on the ground. The deep space in between, the shooting stars representing new energy, new spirits on their way. The spirit guides' color palette depicting either dawn or dusk, the zone between night and day. The spirits are welcoming, the man's drum facing earth, guiding earth to spirit; and the woman's drum facing the star window, guiding spirit to earth. They are singing the Welcome Song. There are four drums in total, the four directions, the four seasons of life. The Old Ones are waving, they are happy to see the traveller again.

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### ABOUT THE ARTIST

My name is Kísikâw ahcâhk iskwêw, Skúzás, or Lisa J. Wilson. I am a Mushkegowuk (Cree) and Státimc (Interior Salish) woman currently living, learning, and creating on Secwépemc territory in BC. I am 25 years old and have been digitally drawing as a hobby since I was 14. Only within the last couple years have I branched out from working with a limited and outdated photo editing software to an up-to-date illustration program (equipped with all sorts of bells and whistles) and it has done wonders in helping me find my style. I come from a family of artists, so creating runs in my blood. My proudest work are the pieces that are inspired by my culture, the more I connect with the land, the language, and the people of my ancestors, the more grounded I feel during my life's journey.

*Tákem nsnekwnúkwa (all my relations),*



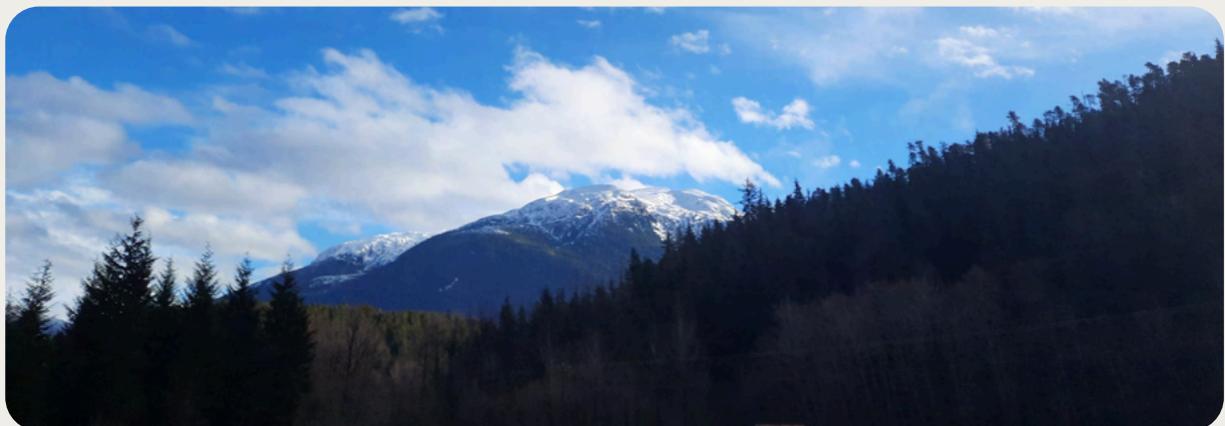
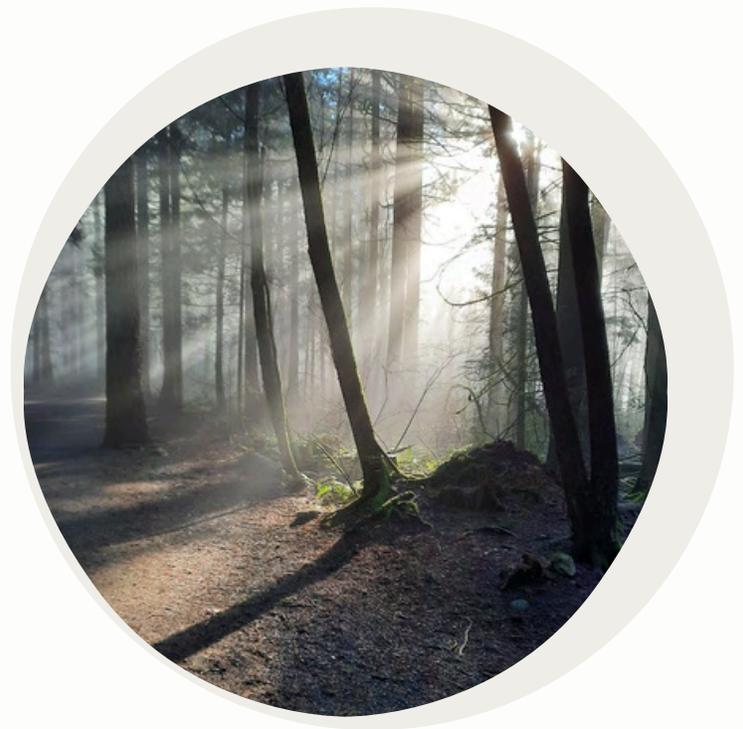
## ABOUT THIS REPORT

### HONOURING CHANGES TO THE INDIGENOUS END-OF-LIFE GUIDE PROGRAM

This evaluation report provides a retrospective snapshot of the Indigenous End-of-Life Guide program as it was implemented between 2019/20 and 2023/24. It documents the program's design, delivery and early outcomes during that specific period. Readers should note that the findings, insights, learnings and opportunities presented in this report reflect this earlier iteration of the program and do not account for the significant shifts in direction, scope, and capacity that were introduced during the program's revitalization in late 2024.

Following the conclusion of the evaluation period, FNHA was awarded a two-year project grant through Indigenous Services Canada to revitalize and enhance the Indigenous End-of-Life Guide program. This new phase of the initiative is rooted in community feedback and evaluation learnings, with a continued focus on supporting First Nations communities in reclaiming and revitalizing sacred traditions and cultural practices surrounding the final journey. As the program moves forward, its evolving trajectory emphasizes resource development and accessibility, followed by curriculum expansion and systems integration.

This report has been published in the spirit of transparency and accountability, and to honour the voices, experiences, and stories shared throughout the evaluation process. The updated vision and pathway forward are described in the final section of the report: The Path Forward.



## ACKNOWLEDGEMENTS

From a First Nations worldview, the end-of-life journey is an important time of significance and transition. Relearning, reclaiming, and revitalizing traditional end-of-life and healing practices held by First Nations is a foundational element of restoring balance and wellness for First Nations communities and members. In-community and culturally safe end-of-life care and grief support can occur when First Nations communities are supplemented to support their members navigate the end-of-life journey, experience grief and heal.

The First Nations Health Authority (FNHA) wishes to acknowledge the FNHA staff, Douglas College faculty, and Elders and traditional Knowledge Keepers who designed and implemented the Indigenous End-of-Life Guide training program, and the individuals who completed the training and are supporting First Nations individuals and communities in BC.

The FNHA Evaluation Team completed this evaluation in collaboration with Qatalyst Research Group Inc. Learnings came from the cumulative insight and wisdom of First Nations community leadership and members, the Indigenous End-of-Life Guide program facilitators and staff, Indigenous End-of-Life guides, and the FNHA nursing and mental health and wellness staff.

We would like to thank all contributors for generously sharing their experiences and perspectives, including the following individuals who consented to being acknowledged by name (listed alphabetically):

AGNES CAMPBELL	DOREEN HOPKINS	ROSE PATTERSON
ANGIE COMBS	HELEN ROSE ROBERTSON	RUTH JOHNNY
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CLIFFORD RYAN	LAURA DAHL	SOLANGE MIGNEAULT
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DEBORAH GREENE	MICHAEL OCHOA	TAMMY MARSEL
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# 1. INTRODUCTION

## 1.1 BACKGROUND

Since time immemorial, First Nations in Canada have held strong traditions of land-based health and wellness, and supported health and longevity through ceremonial and spiritual practices. First Nations traditions and cultural beliefs were inclusive of death, and passing was seen as an integral part of life's journey.<sup>1</sup>

Colonization significantly changed First Nations end-of-life practices and beliefs by imposing European and Christian norms and values that disrupted social and family structures and created new belief systems regarding end of life. This contributed to fear and stigma surrounding dying and death, and a reluctance to discuss or plan for the end-of-life journey.

Colonial policies also affected the availability, accessibility and quality of care provided for First Nations in BC, particularly for those navigating the end-of-life journey. Many First Nations communities still largely lack the required capacity to provide end-of-life care, due to insufficient health human resources to support in-home care, and a lack of long-term and palliative care facilities in or near First Nations communities. First Nations individuals often must travel outside their home community and/or relocate to urban areas to receive end-of-life care, contributing to emotional and financial hardships for families, the medicalization of death, and separation from community and culture.

During the 40<sup>th</sup> Annual BC Elders Gathering in 2016, Elders expressed a need to facilitate and support traditional ways of death and dying for First Nations in BC. In response, the FNHA developed the Indigenous End-of-Life Guide (IEOLG) training program in partnership with Douglas College. The program's design was adapted from the End-of-Life Doula Training Program offered by Douglas College. Program modifications were made in consultation with First Nations Elders to teach the curriculum from the First Nations Perspective on Health and Wellness.<sup>2</sup>

In late 2024, the First Nations Health Authority (FNHA) was awarded a two-year project grant through Indigenous Services Canada to expand and enhance the Indigenous End-of-Life Guide program. This initiative responds directly to community feedback and recommendations gathered during the program's evaluation, with the goal of supporting First Nations communities in reclaiming and revitalizing sacred traditions and cultural practices surrounding the final journey.



<sup>1</sup>Miranda Falk. (July 2019). "[Palliative Care for First Nations People in British Columbia](#)," Master's thesis for the University of British Columbia (Okanagan).

<sup>2</sup>First Nations Perspective on Health and Wellness.

Available from: [www.fnha.ca/wellness/wellness-for-first-nations/first-nations-perspective-on-health-and-wellness](http://www.fnha.ca/wellness/wellness-for-first-nations/first-nations-perspective-on-health-and-wellness).

## 1.2 INDIGENOUS END-OF-LIFE GUIDE TRAINING PROGRAM

The IEOLG training program aims to build upon the existing capacity and strengths of natural helpers<sup>3</sup> within First Nations communities to support individuals and their families during the end-of-life journey. It also encourages respectful and culturally appropriate conversations that help remove stigma around end-of-life planning. The training provides opportunities for participants to develop a deeper understanding of the final journey, diverse Indigenous beliefs and cultural practices surrounding end-of-life; learn about resources available to support individuals and families; and develop a community of practice for guides. Individuals who complete the program are considered Indigenous End-of-Life guides and are expected to apply the skills and knowledge acquired to assist community members during their end of life, either in a professional or voluntary capacity. More information about the program is available on its web page<sup>4</sup> and in a short video<sup>5</sup> (see the links in the footnotes).

An **Indigenous End-of-Life Guide** (hereafter referred to as guides) is a companion who provides a dying individual and their family with practical and emotional support throughout the end-of-life journey. Guides have a flexible role that complements the family's care and services provided by other health care providers (e.g., nurses, physicians, care aides) by working to meet the dying person's needs and wishes and improving the quality of the end-of-life journey. Guides can also support the individual's and family's access to community-specific traditional practices and protocols by working with Indigenous cultural healers and Knowledge Keepers. Guides' flexibility allows them to meet individuals and families where they are receiving care, including at home, as well as in palliative or hospice settings.

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<sup>3</sup>A natural helper is a trusted community member whom people spontaneously turn to for advice, emotional support or practical help with personal or health-related challenges.

<sup>4</sup>Indigenous End of Life Course.

Available from: [www.fnha.ca/what-we-do/healthy-living/end-of-life-journey/indigenous-end-of-life-course](http://www.fnha.ca/what-we-do/healthy-living/end-of-life-journey/indigenous-end-of-life-course).

<sup>5</sup>End of Life Doula – Guiding the Journey to the Spirit World.

Available from: [www.youtube.com/watch?v=QSIs5JfAfTE](https://www.youtube.com/watch?v=QSIs5JfAfTE).

## 2. EVALUATION OVERVIEW

### 2.1 PURPOSE AND SCOPE

This evaluation assesses the relevance and effectiveness of the IEOLG training program design and implementation between fiscal years (FY) 2019/20 and 2023/24. It tells the story of early impacts on participating individuals and communities, and it identifies opportunities to enhance the reach and effectiveness of the training as well as end-of-life care for First Nations as a whole. Learnings are intended to support program planning and ongoing quality improvement, and to provide guidance to the FNHA's partners.

The primary intended audiences are FNHA staff, executive leadership and Board members.

Secondary beneficiaries of the learnings include the IEOLG community, First Nations community leadership and health staff, First Nations Health Council representatives and First Nations Health Directors Association members, and provincial and federal partners, including BC's Ministry of Health and Regional Health Authorities and Indigenous Services Canada.



## 2.2 DATA SOURCES AND ANALYSIS

Evaluators collected data through the following methods:

### Engagement with 115 key informants including:



- 17 FNHA key informants, including six IEOLG program staff, four program facilitators, and seven representatives of other FNHA programs involved in delivering end-of-life care.
- 92 community leaders, including Chiefs, Health Directors and Health Leads.
- 6 practicing guides, representing all five FNHA regions.

A survey of individuals who completed IEOLG training between 2019 and 2023 (response rate: 94/369, 25%).



A review of IEOLG documents, data and files, including training materials, participant data, post-training survey results (response rate: 227/390, 58%) and financial and contractual documents.



A literature review of First Nations traditional and cultural approaches to the end-of-life journey, grief and healing support among Indigenous peoples in Canada, and challenges experienced by Indigenous communities related to traditional and cultural practices during the end-of-life journey.



An environmental scan of similar programs in other jurisdictions.



In the spirit of transparency and reciprocal information sharing, after engagements, evaluators developed summaries of what was heard and returned these to participants for their validation, the opportunity to provide additional input, and their own personal use as per the principles of OCAP.<sup>6</sup>

Evaluators used a strengths-based, two-eyed seeing approach to gather and analyze data, weave together diverse sources of information and draft findings. The key findings and conclusions presented were triangulated and confirmed with additional lines of evidence.

<sup>6</sup>The First Nations Principles of OCAP. Available from: [fnigc.ca/ocap-training/](https://fnigc.ca/ocap-training/).

## 2.3 LIMITATIONS

Despite multiple and diverse lines of evidence and careful triangulation of data with literature, documents and data, known limitations of the evaluation and mitigation strategies employed include the following:

- 1. Limited direct evidence of the impact of guide supports and services on participating individuals and their family members.** As the FNHA does not receive information on the identity of individuals and family members accessing guide services, evaluators had no ability to gather direct input. Given the sensitive nature of this topic and the FNHA's desire to maintain the confidential, privileged relationship between guides and their clients, evaluators chose not to pursue engagement with clients or surviving family members through the guides. Guides' perspectives on client experiences were used as proxy evidence in assessing the reach and effectiveness of their services.
- 2. Recency and non-response biases.** Interview and survey responses may be subject to recency bias, as guides who had recently completed their training would be more likely to complete surveys or respond to interview requests. Although the survey response rates were high overall, the survey was still subject to non-response bias. To reduce the potential impact of these biases, primary data was validated with respondents and triangulated against the responses of other key informant groups and other lines of evidence.
- 3. Financial data.** Some financial information, such as the salary and wages of FNHA staff, are estimates since the program does not have a dedicated staff position and duties are shared among a few staff members.



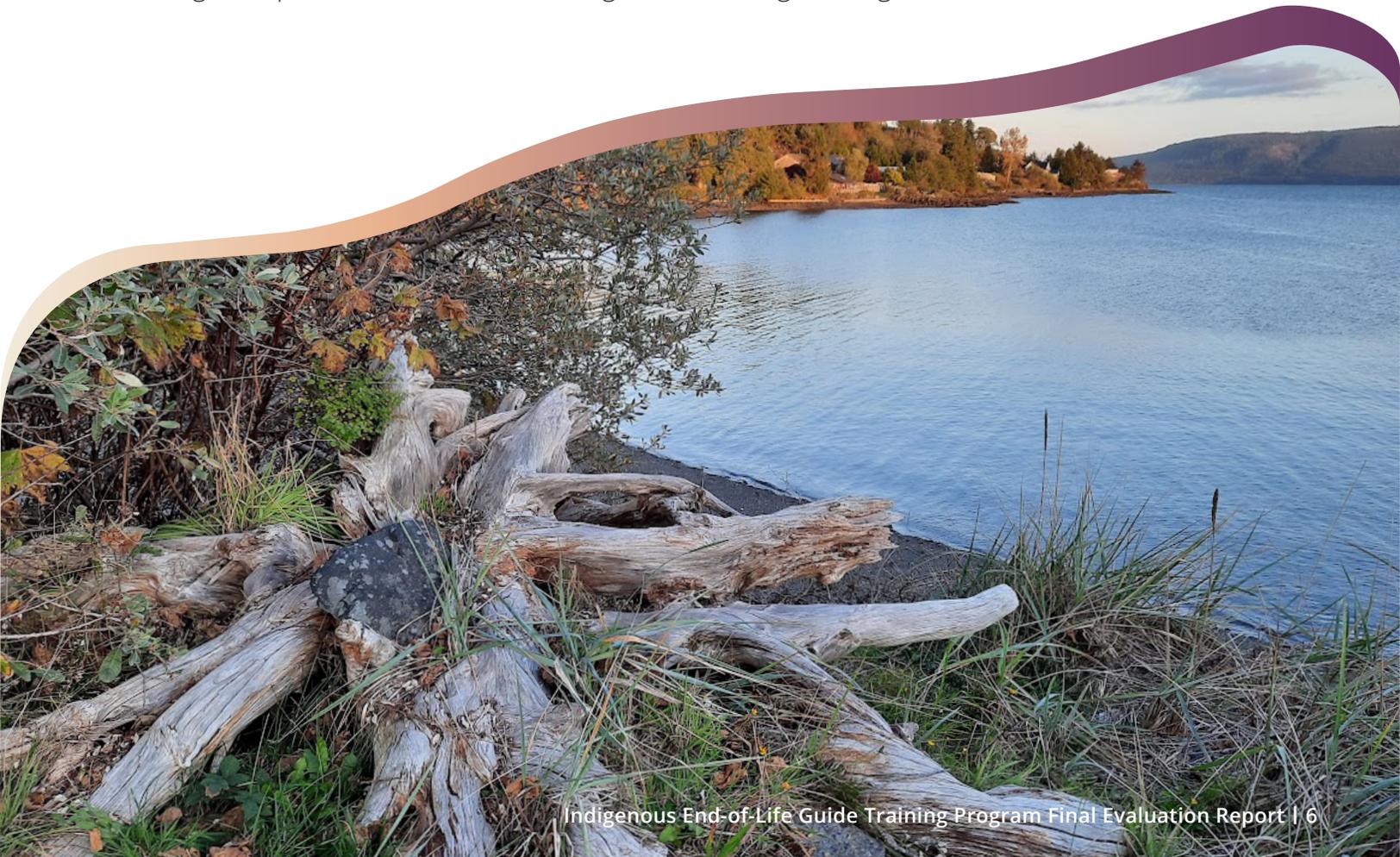
## 3. INDIGENOUS END-OF-LIFE TRAINING PROGRAM

### 3.1 PROGRAM ADMINISTRATION AND GOVERNANCE

The IEOLG program was established through a partnership between Douglas College and the FNHA in 2019. The relationship and respective roles of the two parties are governed by a Collaboration Agreement. The FNHA and Douglas College both hold full intellectual property rights for the curriculum and can deliver the training independently of each other.

Currently, the FNHA independently delivers the training to First Nations communities in BC, and Douglas College independently delivers the training to Indigenous communities elsewhere in Canada. The FNHA and Douglas College come together annually to review and update the curriculum.

Within the FNHA, the program is governed and delivered by Office of the Chief Nursing Officer staff – including a program manager, facilitator and administrative assistant – all of whom work part time on the program for a combined total of 0.75 full-time equivalent. These staff members oversee the program's promotion among First Nations communities in BC, register attendees, recruit local Elders and Knowledge Keepers, book venues, and organize catering and logistics.



## 3.2 FUNDING AND EXPENSES

### Funding Sources

The FNHA funds the IEOLG program and training delivery to First Nations in BC through Home and Community Palliative Care funding received as part of a contribution agreement from Indigenous Services Canada. The program also leverages in-kind community contributions in the form of training venues, staff accommodation and learning materials related to the community's cultural teachings and practices.

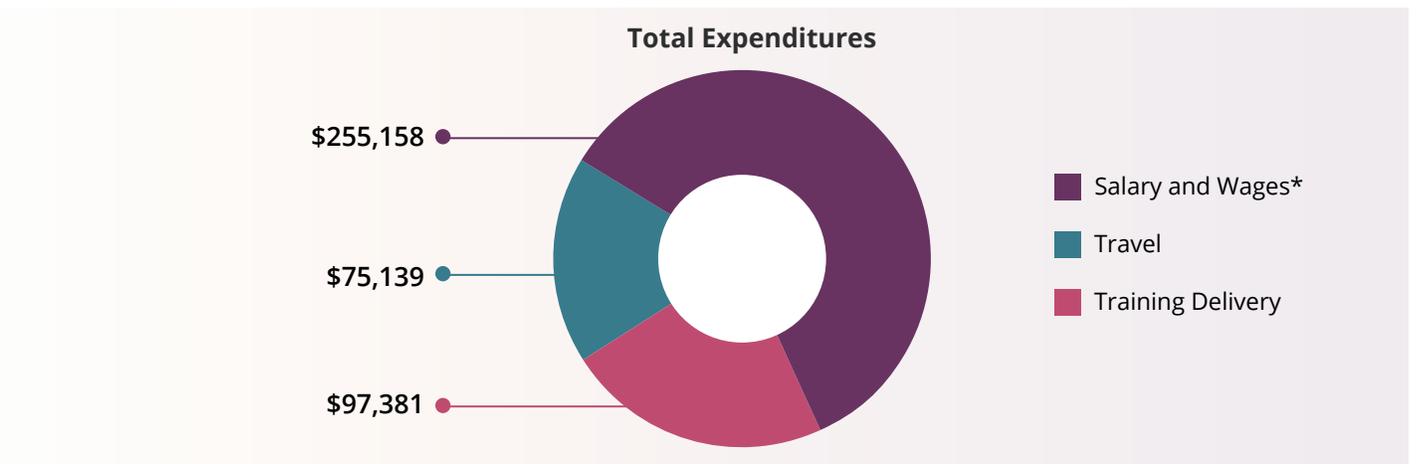
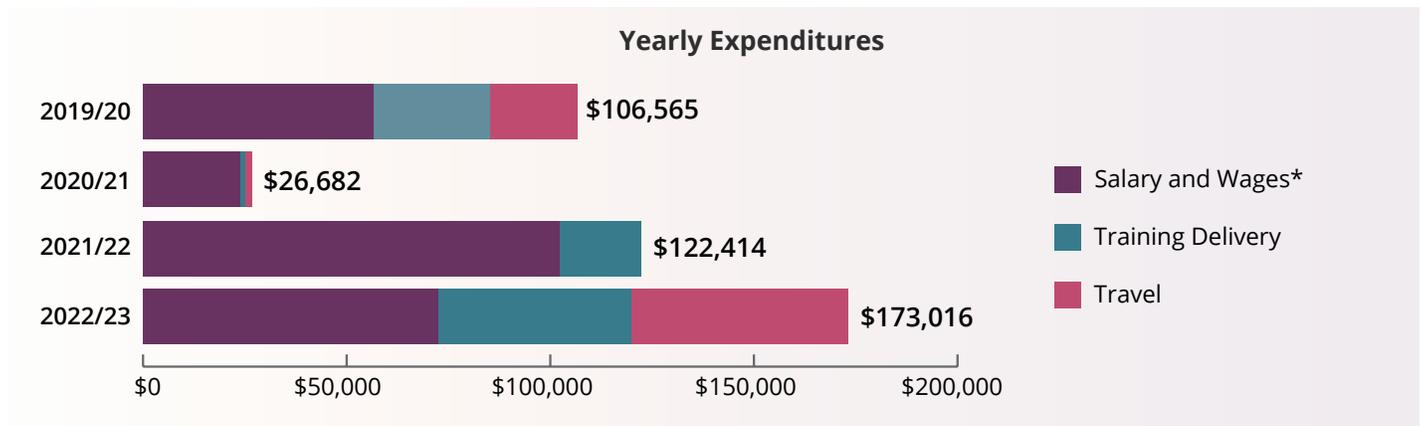
### Expenditures

Between FY 2019/20 and FY 2022/23, program expenditures totalled \$427,678. Over half of this amount (60%) went towards salaries and wages for FNHA staff, payments to Douglas College facilitators, and honoraria for participating Knowledge Keepers and Elders. Twenty-three per cent (23%) went towards training coordination and delivery, and 17% funded participant and facilitator travel.

As the program scaled up, expenditures increased from \$106,565 in FY 2019/20 to \$173,016 in FY 2022/23. In FY 2020/21, only \$26,682 was spent on the program, largely due to the COVID-19 pandemic response restrictions on in-person gatherings and the FNHA being in Level II Emergency Response.



**Figure 1. Yearly and total expenditures of the IEOLG program, FY 2019/20 to FY 2022/23**



\* The Salary and Wages category includes FNHA staff salaries and wages, payments to Douglas College for facilitators, and honoraria for Knowledge Keepers and Elders. Staff salaries and wages have been estimated based on program staff's perceptions of the proportion of hours they spent on the IEOLG program compared to other work responsibilities.

### Training Cost per Participant

Douglas College facilitators charge a fee of \$675 per participant. From 2019 to 2022, most training sessions were delivered by Douglas College facilitators at an average cost per participant of \$2,288 for in-person delivery and \$791 for online. Since 2022, FNHA staff facilitators have delivered training at an average cost per participant of \$1,613 for in-person and \$131 for online.

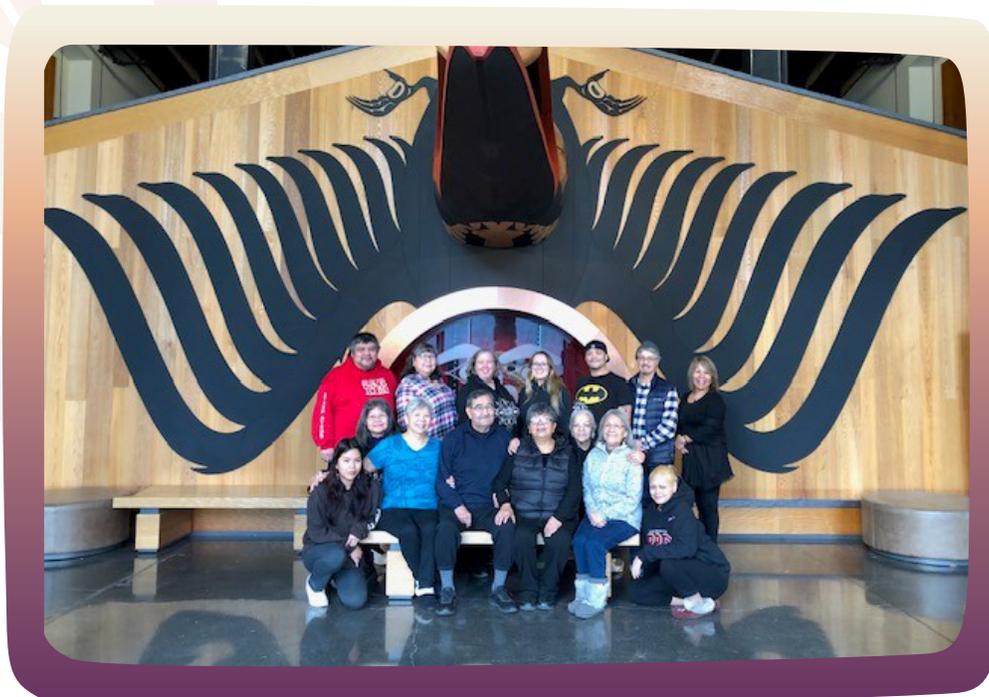
### 3.3 TRAINING DESIGN AND DELIVERY

#### Program Design

The IEOLG program is an adaptation of Douglas College's End-of-Life Doula program. With input from Elders and Knowledge Keepers, the FNHA and Douglas College collaboratively incorporated First Nations end-of-life traditions, values and practices into the curriculum, and adapted the facilitator guidebook and participant workbook to reflect Indigenous participants' needs and priorities. The FNHA added Knowledge Keepers as co-facilitators and included cultural support to facilitate trust and relationship-building among participants within respectful, safe learning environments.

Currently, the FNHA offers training at no cost to all eligible members of First Nations communities in BC. In-person sessions are organized annually in each region, and online sessions are offered for First Nations people from all regions. Upon request, the FNHA also delivers community-specific trainings. For in-person sessions, the FNHA covers participants' costs related to travel, accommodation and meals.

Individuals who complete the program are provided a Recognition of Completion certificate issued by the FNHA or Douglas College.



## Eligibility

The IEOLG training is designed for First Nations people living in BC who provide, or plan to provide, care for individuals and families navigating the end-of-life journey or experiencing grief. Currently, the training is targeted towards individuals working in non-regulated health care roles, such as care aides, Indigenous patient liaisons and natural helpers within community. Occasional exceptions are made for non-First Nations individuals who provide care in First Nations communities and are nominated by community leaders. Regulated health care providers such as physicians, nurses and social workers are ineligible. In rare cases, exceptions can be made for former and non-practising regulated care professionals (e.g., nurses, social workers) to attend the training.

## Training Promotion and Nomination of Trainees

IEOLG program staff promote the program and upcoming training opportunities to Health Directors, community nurses and regional FNHA staff through regional email distribution lists. FNHA regional staff promote the program to First Nations community leadership through regional communication channels, such as newsletters.

Potential participants who are living in First Nations communities in BC are nominated by community Chiefs, Health Directors and Health Leads. For potential participants who are living in urban areas or away from their home communities, the FNHA requests support from a manager and an explanation of how they plan to use the skills and knowledge. Participants are screened for program suitability to ensure they work or volunteer in fields related to end-of-life or grief care, have personal experience in providing end-of-life care, or have other plans to apply the skills and knowledge taught through the program.

Following completion of each training session, an email notification is sent to the distribution list notifying community health leaders that new guides have been trained in the region. Contact information is shared for newly trained guides who provide consent.



## Training Delivery and Reach

The FNHA offers the IEOLG training program both in person and online. Online sessions are only offered in winter when it is difficult to travel.

Training is co-facilitated by a Knowledge Keeper with expertise in First Nations knowledge and cultural practices around the end-of-life journey, and an end-of-life care educator with expertise in western palliative care practices. Whenever possible, Knowledge Keepers local to the area where the training is being delivered are identified and recruited by the FNHA in collaboration with local First Nations communities.

The training is delivered over four days, with each day focused on one module. Facilitators deliver the curriculum through presentations and videos, guided conversations and question-and-answer periods. In some sessions, guest presenters are invited to speak to specific topics of interest (e.g., funeral planning, available local palliative services and Indigenous health care services).

Cultural support is provided during training sessions by Knowledge Keepers from the Indian Residential School Survivors Society, Tsow-Tun-Le-Lum Society or other cultural support workers. This often includes brushing, smudging, singing, drumming, energy work, wellness wheel exercises and counselling. During online training, cultural support is offered in a separate virtual breakout room.

Between January 2019 and October 2023, 27 training sessions were delivered. Approximately two-thirds were conducted in person, while the remainder were held online. Online sessions were introduced in 2021 due to pandemic restrictions and were the only format offered that year. In 2022 and 2023, both in-person and online options were available.



**27+**

**sessions delivered between  
2019/20 and 2022/23**

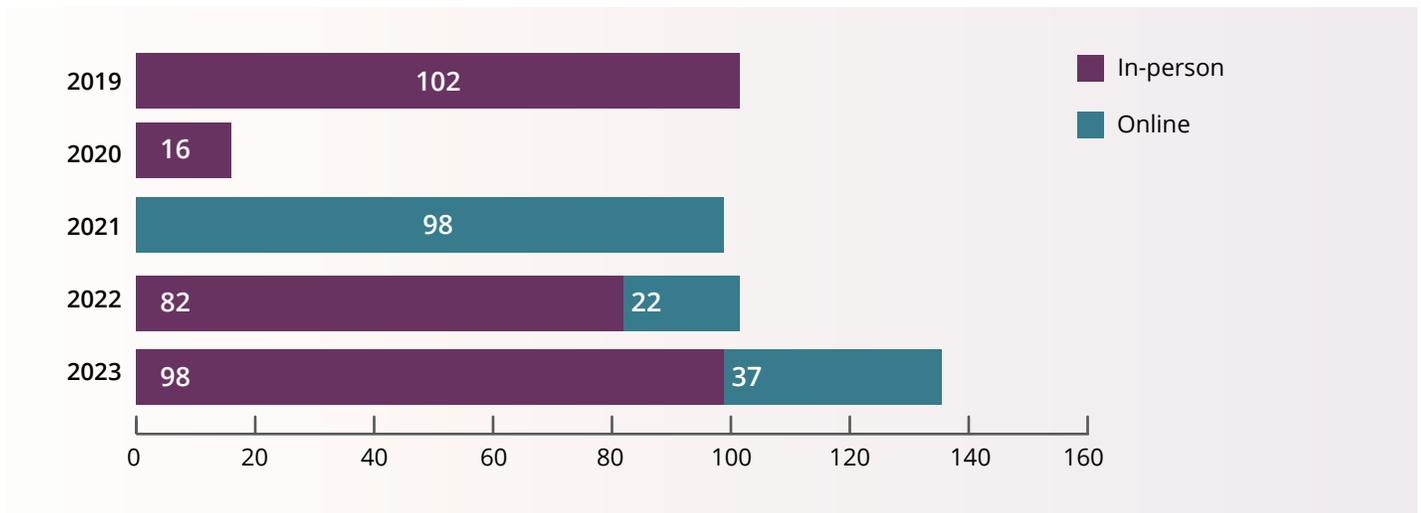


**67%**

**of people who attended the  
training attended in person**



Figure 2. Online and in-person training participation, 2019 to 2023



A total of 455 participants completed the training, representing 163 First Nations communities. A large majority (80%) of participants worked in related fields, for example, as care aides, support workers, community health representatives (including Health Directors, Elder coordinators, paramedics), cultural and spiritual workers, and Aboriginal or Indigenous patient liaisons. The remainder (20%) identified as volunteers or natural helpers within their community. All participants were already providing end-of-life services and supports to community members and sought to gain additional knowledge and skills to enhance the relevance and quality of their existing services to better meet individual and community needs.

**455**

people have completed the training



**163**

First Nations communities in BC had members complete the training

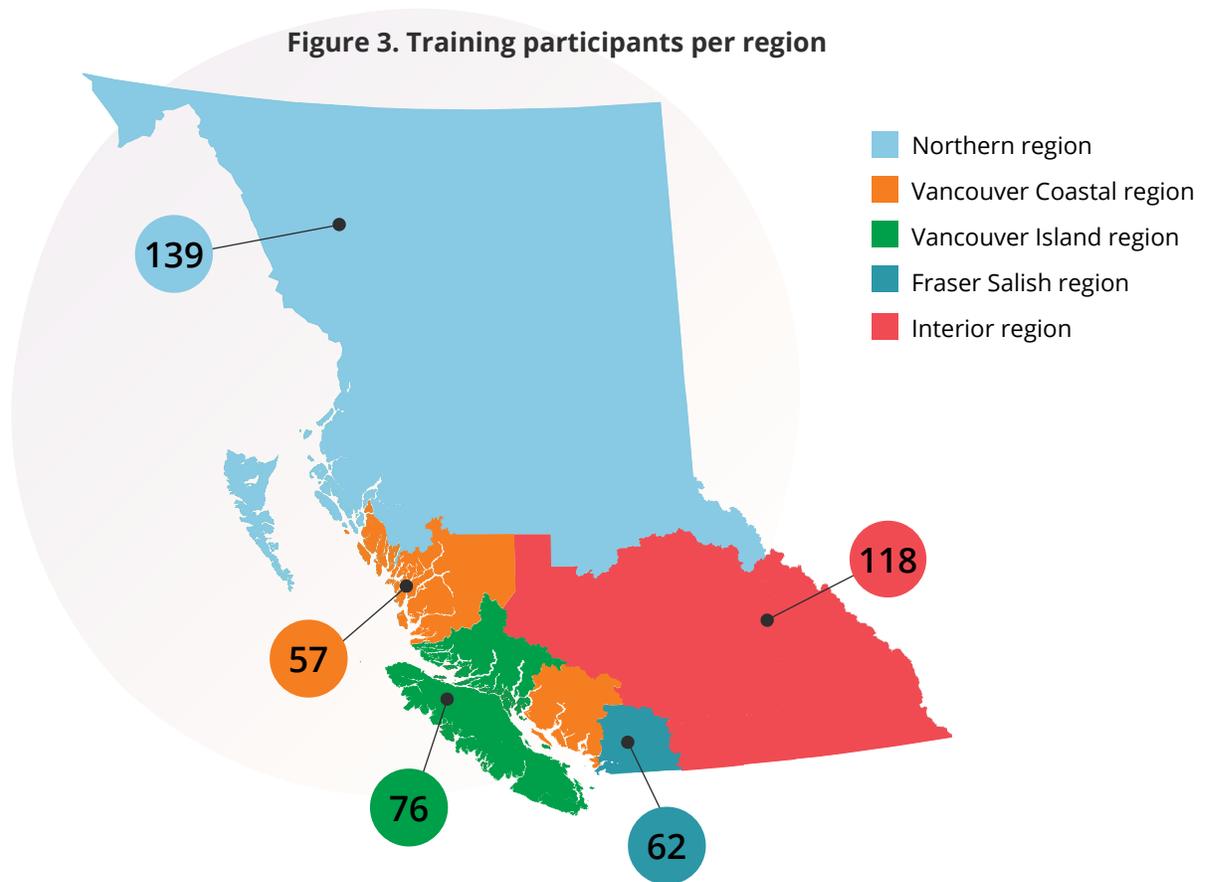


**80%**

of people who completed the training work in health and wellness role



Individuals from all regions participated, and the regional representation aligned with the geographic distribution of the First Nations population in BC.



## Curriculum

The curriculum consists of four modules, each focused on a specific area of practice.

Module 1	Module 2	Module 3	Module 4
			
Provides context on end-of-life care, both from a western palliative care lens and traditional First Nations worldview and situates the role of a guide.	Outlines ethical and legal responsibilities, effective communication and facilitation skills.	Provides greater practical insight into the end-of-life journey, resources and supports for individuals and their families, and self-care strategies for guides.	Focuses on advance care planning, funeral practices and navigating grief.

Guides leave the IEOLG training with informational resources to assist them in providing care. Resources include the Indigenous End-of-Life Guide workbook, advance care planning materials, end-of-life care information, a list of community resources and a template for collating contact information for relevant local providers to complete.

## ELDER/KNOWLEDGE KEEPER JO-ANNE GOTTFRIEDSON

Jo-Anne is a proud mother of two daughters, a traditionally adopted son, and a grandmother of five grandsons and a beautiful granddaughter; she has five step children and many adopted children and grandchildren from various nations across Canada and the U.S. She is married to Reverend James Isbister from the Cree Nation, Ahtahakakoop Sandy Lake, Saskatchewan.



Jo-Anne is formally educated at Simon Fraser University and is a retired teacher of Secwepemc language and culture at the Nicola Valley Technology Institute and Aboriginal Tourism BC. She is also an Elder Facilitator of the Indigenous End of Life Guide course, among many other leadership, cultural and spiritual roles.

Jo-Anne credits her accomplishments and work as a testimony to her 'traditional' education shared by her parents, grandparents and various other Elders/teachers that she has met along her journey. She believes that the traditions, beliefs, teachings, and language of our ancestors is just as, or more, important than any other education First Nations can achieve.

## Elder/Knowledge Keeper Jo-Anne Gottfriedson gifted these words on the IEOLG program

"A Final Journey is a true blessing and is sacred.

Indigenous Peoples in British Columbia highly view the End of Life's journey as sacred.

The final journey and ways of honouring the loved ones who have journeyed to the Spirit World are very diverse and unique to each nation. The loved one is prepared with the utmost respect and is honored with ceremony.

During our life's journey we are born, we achieve, and we are prepared to meet with our ancestors. Even though it is a very difficult time that affects our hearts, minds, bodies and spirit, it is vital that we always engage in the highest level of love, and respect.

The Indigenous End-of-Life Guide program is a very important means of providing techniques and developing understanding of Indigenous ways of knowing to provide support to guide those who are preparing for their final journey and provide unconditional assistance. It is a true honour to be one of the team members who provided the clinical and cultural traditional ways of the program. This program also was a powerful way to fully support numerous Indigenous communities engaged in the goals of providing absolute pride and honour to the individual on their final journey, to their loved ones, to their community and their nation."

Kukstsetemc! And with honour  
Elder/Knowledge Keeper  
*Jo-Anne Gottfriedson*

### 3.4 ONGOING SUPPORT FOR GUIDES

The FNHA organizes quarterly virtual discussion groups and events to facilitate ongoing learning and sharing of wise practices among guides. Guides receive updates and invitations to register for the events via email. Between April 2021 and January 2024, 14 events have been held, covering a diverse range of topics including advance care planning, medical assistance in dying, wills and estate planning, difficult conversations, as well as healing and sharing circles. Attendance has increased from three to five participants per session in 2021 to over 20 in 2024.

Guides are also encouraged to participate in local communities of practice, where they can come together to support one another and share knowledge and wise practices. These independently organized communities of practice can include regular email or social media communication, and/or online or in-person meetings.

Finally, guides are encouraged to support their own self care by accessing cultural support in their community through the Indian Residential School Survivors Society, Tsow-Tun-Le-Lum Society or other community resources.



## 4. SHARING SUCCESSES AND ACHIEVEMENTS

### 4.1 REVITALIZING FIRST NATIONS KNOWLEDGE AND CULTURAL PRACTICES

#### Facilitating the Reclamation and Revitalization of Traditional and Cultural End-of-Life Knowledge and Practices

All lines of evidence indicate that the IEOLG program supports the reclamation and revitalization of traditional and cultural end-of-life beliefs and practices by imparting knowledge from Elders and Knowledge Keepers to guides. Guides subsequently share the learnings with the individuals and families they serve and facilitate further connections to Elders and Knowledge Keepers within communities.

As previously described, the IEOLG training program curriculum is designed and delivered in partnership with Elders and Knowledge Keepers from First Nations in BC and incorporates traditional knowledge and cultural healing practices. Nation- or community-specific training delivery especially supports the reclamation and revitalization of local knowledge and customs.

Guides report imparting the knowledge they acquire through training to the individuals and families they serve, while honouring the diverse perspectives, traditions and customs of individual families. Guides also report connecting the individuals and families they serve with community Elders and Knowledge Keepers, further bridging connections and supporting greater access to traditional practices surrounding end-of-life.

“The training helped me have those difficult conversations to ensure that Indigenous values around death and dying are respected.”

– Guide

## Supporting Community and Self-Determination and Strengthening Local Capacity

**The IEOLG program supports community and Nation self-determination by following a community's direction on participant selection and incorporating guides into community health and wellness teams or cultural support services and networks.**

Community leaders authorize who from the community is eligible to attend the training and determine how the trained guides are integrated into community health teams and other cultural support services and networks, in line with each community's unique context and culture. Following each community's direction resulted in successfully recruiting participants from targeted occupations who had the desired motivation and enthusiasm to use their acquired skills and knowledge to benefit their communities

**The training effectively targets and strengthens the capacity of individuals in communities who are already providing end-of-life care or grief support, and to a lesser extent, community champions and natural helpers.**

A large majority (80%) of participants worked in related fields, for example, as care aides, support workers, community health representatives (including Health Directors, Elder coordinators, paramedics), cultural and spiritual workers, and Aboriginal or Indigenous patient liaisons. The remainder (20%) identified as volunteers or natural helpers within their community. All participants were already providing end-of-life services and supports to community members and sought to gain additional knowledge and skills to enhance the relevance and quality of their existing services to better meet individual and community needs.

"I am the Elders Coordinator, and we have had too many losses in the past couple of years. I needed to know how to make it manageable and support the Elders in our community."

- Guide



"I have been a home support worker for 23 years and, in that time, I have experienced a lot of death. To have this training means a lot - to help the family who may not understand that death is a very beautiful, peaceful experience, although, yes, it hurts."

- Guide



## 4.2 TRAINING AND SUPPORTING GUIDES TO PROVIDE END-OF-LIFE SERVICES

### Accommodating In-Person and Online Training Delivery

In-person training is strongly preferred, as it supports relationship-building among participants and promotes a culturally safe and wholistic learning environment. Online training is suitable for individuals who are unable to leave their communities or who work with immunocompromised patients.

Most guides, as well as program staff and facilitators, strongly prefer in-person training. The in-person learning environment is considered more conducive to the delivery of sensitive subject matter, relationship-building among participants, and offers greater assurance of a culturally safe learning environment, including through the provision of on-site cultural supports.

When asked what they liked about the training, surveyed guides shared:

“Personal interactions with the facilitators and participants and being able to feel the emotions and offer support to those who needed it by being present with them to hear their story.”

– Guide

“Sharing views from diverse locations and cultures is ideal for understanding what each area experiences and the different cultural protocols. Getting to know the other participants and presenters during breaks, evenings, etc.”

– Guide

The most cited benefits of online delivery include easy accessibility, being able to provide training to individuals who are unable to leave their community, and preventing exposure to COVID-19 and other infectious diseases. This last benefit may be particularly important to individuals who are caring for immunocompromised patients. Challenges and limitations of online training included low internet speed in many communities, lower audio quality, diminished relationship-building opportunities, reduced psychological safety when participant cameras are turned off, the fatigue associated with looking at a screen for a long period of time, and the inability to engage in hands-on cultural activities.

IEOLG program staff and facilitators strived to make online sessions interactive and create opportunities for virtual cultural support. These included mailing traditional medicines to participants in advance, having cultural support workers guide participants on how to smudge or brush themselves, and providing one-to-one sessions in virtual breakout rooms.



## Meeting Trainees' Informational Needs and Learning Objectives

**A large majority of surveyed guides are satisfied with the program and had their learning objectives met through the training. The expertise, humility and kindness of the facilitators, Elders and Knowledge Keepers, as well as the inclusion of First Nations traditions and customs, are key contributing factors to participants' satisfaction.**

Most surveyed guides (88%) reported that they were satisfied or very satisfied with the program, and almost all (93%) indicated in the post-training questionnaire that the session length was appropriate.

Guides reported that the training met their objectives to learn about the end-of-life journey and care from both Indigenous and western perspectives, and how to support individuals and families navigating the end-of-life journey. The participants used terms such as "life changing", "Indigenous-focused", "heartfelt", "respectful" and "lifelong useful" to describe the training. They agreed that the training was highly impactful and shaped their views on life, helping them to explore a part of life that most people avoid looking at.

Guides felt the facilitators were very knowledgeable about the topics discussed and communicated complex and sensitive topics in simple and impactful ways. Guides felt safe and supported to learn and share as a result of the facilitators' demonstrated compassion, and most (84%) agreed or strongly agreed that the training was culturally safe.

Guides also found the Knowledge Keepers' insights, personal stories and lessons from their own lives impactful. They enjoyed meeting people who are working in similar fields and have common interests. Guides noted that the workbook was helpful, since it summarized critical information they could reference when providing care in their community.



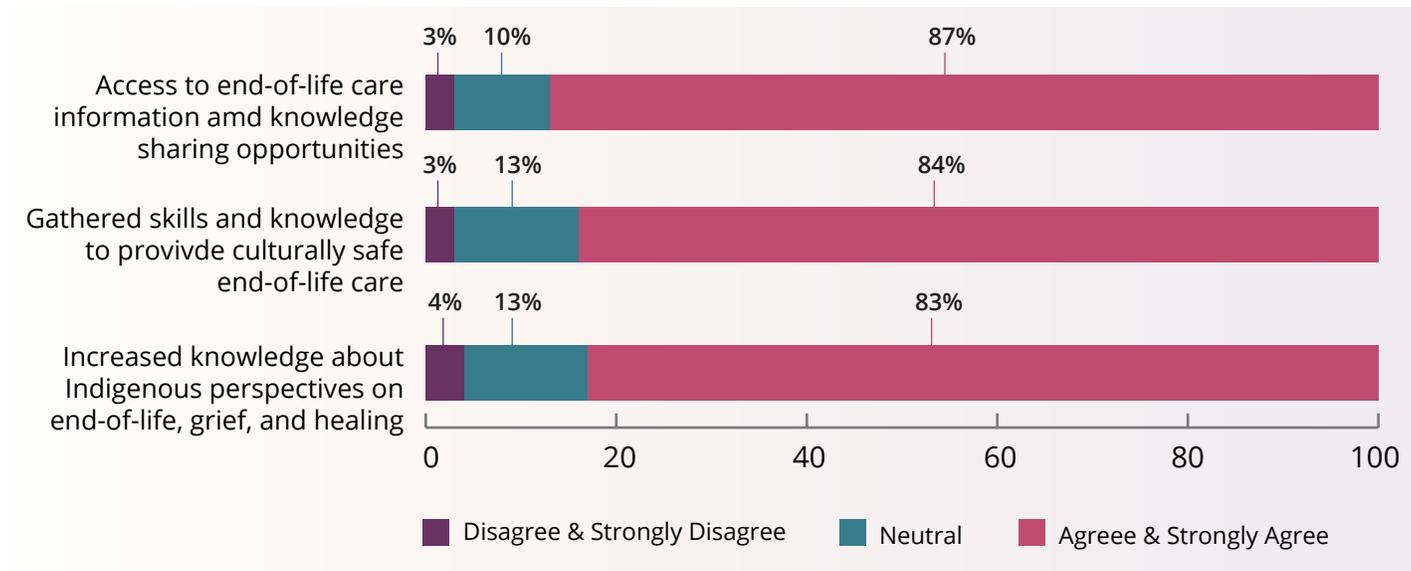
**"The training session was done in a way that was comfortable and the instructor was very kind. The days went by very quickly."**

**- Guide**

Guides report increased access to end-of-life care information and knowledge-sharing opportunities, enhanced skills and knowledge to provide culturally safe end-of-life care, and increased knowledge about Indigenous perspectives on end-of-life care, grief and healing.

A large majority of surveyed guides reported that the program increases access to end-of-life care information and knowledge sharing opportunities, provides participants with skills and knowledge to provide culturally safe end-of-life care, and increases participants' knowledge about Indigenous perspectives on end of life, grief and healing (see figure below).

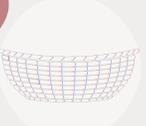
**Figure 4. Participants were highly satisfied by the training, particularly on knowledge and skills**



Most guides feel better prepared to support their community following the training, with the most valuable learnings including First Nations cultural and traditional beliefs and customs, strategies for providing effective communication and emotional support to individuals and families, and strategies to support advocacy for clients navigating the health care system.

The following figure depicts the key learnings guides highlighted as being most valuable.

**Figure 5. Guides' most valuable learnings**

-  1 First Nations cultural and traditional practices, beliefs and values around the end-of-life journey.
-  2 Providing care and emotional support to individuals and families navigating the end-of-life journey to help individuals and families be at peace.
-  3 Effective and respectful communications skills, including demonstrating empathy and vulnerability, actively listening and being prepared for sensitive conversations.
-  4 Strategies to advocate on behalf of individuals and their families.

After the training, most participants mentioned that they felt confident and inspired to apply the knowledge and skills they acquired. Almost all guides felt that their newly acquired knowledge will help them support others at the end of life. More than three-quarters indicated that they already had a plan of how they would assist members when they return to their communities.

“The IEOLG training program helped me to move past the fear and discomfort of discussing death and dying. I realized that talking about it was empowering because it’s so personal. It’s a strength to address it and a comfort to be heard. It is so important that FNHA continue to offer the program to community members.”

– Guide

“[I learned from the training] when to give [each] family time, information and support, and when not to, how to provide information around care and expected death, and how to approach families in distress. I also learned that it was not only okay, but [that I should] approach and ask the community Elders for guidance. I have better insight and knowledge that there are unique protocols in place for each family. I learned that it was okay to ask, and to find out what they are. I have a better understanding of how to support grieving families before, during and after a death.”

– Guide

## Providing Ongoing Support and Integrating Guides in Community Networks

The program is successfully tailoring ongoing post-training learning opportunities to meet guides' expressed learning needs and there has been moderate success in encouraging communities of practice. Guides are successfully being integrated into community support networks that include leaders, Elders and health and wellness providers.

The program is successfully tailoring ongoing post-training learning opportunities to meet guides' expressed learning needs, such as sessions on grief and healing, Indigenous perspectives on and supports for cancer, and advance care planning. Program staff and facilitators have also provided ongoing support to guides, as requested. Guides shared that these relationships have reinforced their confidence and prepared them to provide end-of-life care to their community members.



“What has helped me the most is my conversations with [the IEOLG program coordinator] – she has been incredibly supportive and has validated my approach and learnings. I think this is essential for each IEOLG to have a mentor like her, otherwise it feels like I am doing this on my own.”

– Guide

There has been moderate success in encouraging communities of practice. About one-third of surveyed guides indicated that they maintained connections with other guides following the training, either through communities of practice or interpersonal relationships. For example, guides in the Vancouver Island Region have an active Facebook group where they regularly engage in discussions.

Importantly, guides are being integrated into community support networks that include community leadership, Elders, colleagues and other members of the health team such as hospice staff, social workers, nurses and counsellors.



**“The course created curiosity. I have spoken to the local leaders, Elders and individuals regarding death and dying. These conversations have been my biggest support.”**

**– Guide**



## SUE WILSON CHEECHOO'S STORY (INTERIOR REGION)



**INTRODUCTION:** Wâciye (hello), my name is miskahnaksko (the woman who speaks with the turtle), English name Sue Wilson Cheechoo. I am from the Mushkegowuk territory, of the ililiwuk (People of the land) of western James Bay, Ontario. Four of my children are members of Xaxli'p First Nation in BC. Their dad is the late Allen (Paso) Adolph, and their grandparents are Shirley Wilson and the late Maggie and Lawrence Adolph. I live in St'at'imc territory, amongst my family, including two ilu sons, grandchildren and friends.

### A Natural Extension of Learning

Sue's career has been dedicated to supporting the health and wellness of First Nations Peoples. During her forty plus years working in health, Sue has been a long-term care aide, Registered Nurse, Midwife Apprentice, First Nations Health Director, and she has carried out First Nations health education, planning, community development, and community-owned research.

In 2021, Sue volunteered to train as an End-of-Life Guide to add to her learnings in her winter years. Seeing the gaps around end of life, Sue wished to support individuals, and their families during this sacred time in their lives. Through the IEOLG training, Sue gained new knowledge and skills to support families at home and in health care provider settings.

### Offering Compassionate Support

Community members learn of Sue's volunteer supports mostly through word-of-mouth. Sue can provide support by being a listening ear for someone who has concerns, questions or wants to talk about end-of-life preparation, which can be months or years before death. Her supports can extend up to four years following the transition to the Spirit World, depending on the family's preferences

"As I listen to the individual or family's request, I determine the kind of support that I may be able to offer. It's their journey and my role is to be a helper. They may have questions related to understanding the services around end-of-life care and/or they may want to understand the signs of transition. They may want me to visit or to talk with them on the phone or text. For me, it is of the utmost importance to support the wishes of the one who is transitioning."

By working closely with individuals, families, and health providers, Sue supports end-of-life care to be carried out with respect and dignity, similar to the supports she offered mothers and families around births. Her quiet, wholistic and culturally safe approach honours the individual's life journey, and helps families find comfort.

"Life is a ceremony, and preparation for birth and death are important parts of that ceremony. It is an honour to help First Nations families, and it is an honor to support their loved one who is preparing to leave to the Spirit world."

### The Importance of Continuous Learning and Mentorship for Guides

Sue believes in the value of ongoing mentorship for End-of-Life guides, to support continuous personal development and application of the training. She appreciates her ongoing support from IEOLG program facilitators and suggests guides could benefit from ongoing mentorship support.

### 4.3 SUPPORTING FIRST NATIONS INDIVIDUALS AND THEIR FAMILIES

#### Supporting Over 400 First Nations Individuals and their Families

**While the actual number of individuals and families served by guides is unknown, conservative estimates based on guide self-reported data indicate a minimum of 400 to 650 individuals and families have received support.**

The total number of individuals and families that have benefited from guide services and supports is unknown, as guides do not report to the FNHA. A 2023 survey of guides found that 20 per cent of respondents had supported one to three individuals or families; 43 per cent had supported four to 15 individuals or families; and 16 per cent had supported more than 16 individuals or families. From these findings, it can be estimated that that 400 to 650 individuals and their families have received services from guides, at a minimum. A key reason that these numbers are a low estimate is because the 2023 survey was mostly responded to by recent graduates who had not yet had sufficient time to grow their services.

About 21 per cent of the respondents who indicated they had not yet supported individuals and families cited very recent training completion, pandemic restrictions, lack of referrals and awareness of their services, and lack of compensation as factors impeding their provision of services and supports to community.

How often guides provide their services varies from person to person, and is dependent on many factors, most importantly on their own availability and capacity as well as community need. Overall, guides indicated that their practice grew over time as community members became more aware of their services.



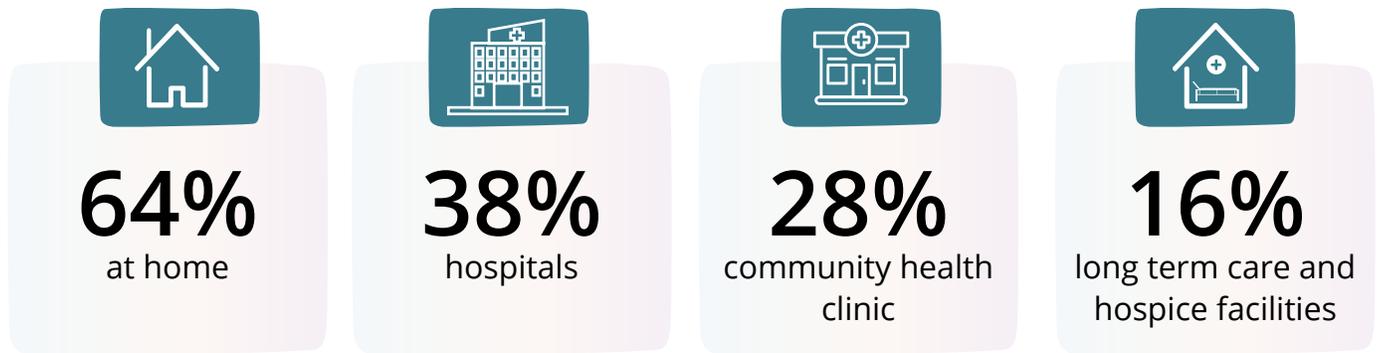
## Increasing Accessibility of Services through Availability in Diverse Settings and Locations

Guides are able to meet community members where they are. The majority provide services within an individual's home. Many guides also support culturally safe care and provide navigation services in hospitals, health clinics, and long-term care and hospice facilities.

Guides offer their services in a variety of settings, depending on what is most comfortable and convenient for individuals and families. Survey findings revealed that the majority of guides assist individuals at their home, and some also provide services in hospitals, community health clinics and long-term care facilities. Services are primarily provided in person, but can also be provided over the phone if needed.



**Figure 6. Locations where guides provide their services**



\*Results from a survey of all training participants. The survey had a 25 per cent response rate and 75 per cent of respondents had been trained within the last two years.

## Facilitating Family Discussions, Bringing Peace and Comfort, Supporting Advance Care Planning and Reducing Stigma

**Guides have facilitated sensitive family discussions around the end of life and advance care planning, and funeral and estate planning. The First Nations-specific culturally safe navigation support, and empathic trauma-informed approach have helped reduce stigma and improve the end-of-life experience for community members and their families.**

Learnings from the interviews, surveys and case studies indicate that guides have facilitated family discussions on end of life (including traditional and cultural end-of-life knowledge and practices), provided culturally safe and responsive support to individuals preparing wills and Advance Care Plans, assisted individuals navigating the health system and funeral planning process, and helped reduce stigma surrounding the end of life.

About half of surveyed guides reported having facilitated family discussions around dying and grief, which included conversations regarding the end-of-life journey from a First Nations perspective and the individual's condition, feelings, advance care plan and legal paperwork. Guides described having provided critical emotional support to members without family to assist them.

Guides described how the family discussions they facilitated helped families reach a shared understanding of needs, goals and protocols, and prevented unnecessary challenges and conflict during a loved one's final days. Guides noted how individuals often struggle to voice their final wishes to family members who were experiencing an overwhelming emotional response and described how they helped bridge this gap by serving as a key liaison between patients and their families by facilitating difficult conversations.



**“Sometimes the client hasn’t spoken to the family about their approaching death. It’s like an elephant in the room, but the client acts like doing alternative medicines will extend their life. The client may go through ups and downs and it confuses the family. Family members think: ‘What is my loved one going through and what am I supposed to be doing?’”**

**– Guide**

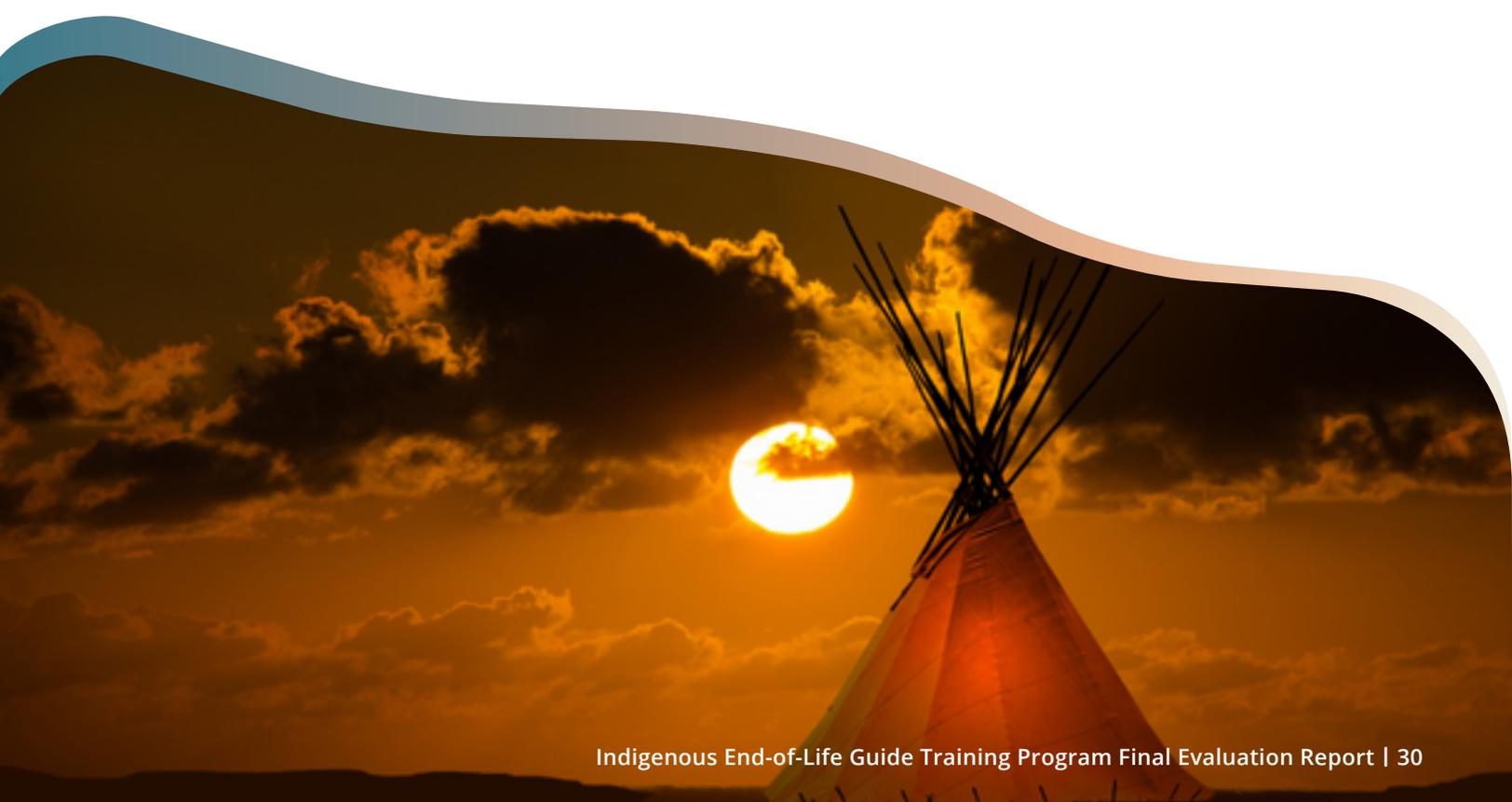
About one-third of surveyed guides shared that they have helped individuals and families with care planning, including sharing information to support decisions regarding their location for their final days (e.g., at home, hospital, hospice, etc.), type(s) of available services to access (e.g., traditional healers and other Knowledge Keepers, palliative care), legal paperwork and funeral arrangements.

**“Some members are adamant about not wanting to go into long-term care. That is a tough conversation I need to have with individuals and then get them set up with the health care team, nurses, and doctors in their communities so that the paperwork is done and people are able to pass peacefully.”**

**– Guide**

**Some guides advocate on behalf of clients to improve the quality of care and promote cultural safety and humility among health care providers serving the community. This includes promoting an understanding of, and respect for, traditional customs and protocols.**

A small number of surveyed guides shared that they advocate on behalf of clients or their community to ensure patients receive the best possible care. Advocacy often involves coordinating with medical teams to improve care and working with funeral homes and provincial government representatives to ensure official procedures (e.g., autopsies and testing) are aligned with traditional practices (e.g., burial within four days of passing).



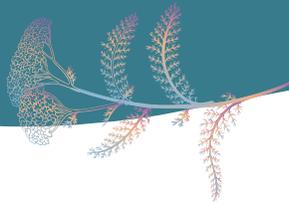
**Guides provide valuable emotional support and connect individuals and families to other resources including Elders, Knowledge Keepers, social workers, hospice workers and grief and loss counsellors.**

Guides have played a key role sharing information about, and connecting community members with appropriate resources, including funeral homes, Elders and Knowledge Keepers, and grief and loss counsellors.



“A lady was in hospital. I was able to bring her cultural support from the community such as brushing and returning soul and comforting heart, and discuss who and what food and services she wanted to have in the room, where she wanted to be buried, etc. I do not practice cultural methods, but I am not there to take that away, I want to add to that. Encourage them to find comfort.”

– Guide



Some guides described providing emotional support to families, before, during and after a loved one's passing. These services often included conversations around grief and accepting loss, healthy strategies to process grief and manage stress, and referrals to grief and bereavement supports in their community or through hospice. Guides shared that their services helped families to understand the end-of-life journey and legal processes, decreased stress and supported decision-making processes.



"You have to be a good listener and let them lead the conversation. It's their journey and you are there as a helper. [The conversation] can be related to ceremonial practices, getting documents in order, the illness the person is experiencing, or questions about finances. That can bring peace to them."

– Guide



"Some families are scared and confused, and just to have someone there guiding lessened the fears. I help by asking for positives and negatives to the situation and support the family to reach a decision."

– Guide



## CONNIE JOE'S STORY (FRASER SALISH REGION)



**INTRODUCTION:** My name is Connie Joe. I am from Chawathil First Nations. My dad is from Chawathil Larry Joe. My late mom is from Shxw'Ow'Hamel First Nation. I enjoy learning in so many areas in life as long as I can provide assistance to others in a good way with a good mind, heart and spirit. I have learned to bead in the last year and has become my biggest hobby and passion to express emotions through color and design. It was interesting to be a part of this as the title catches people off guard, but it is an important topic, and I was glad to have learned about it. Kwos Hoy

### PURSuing A CALLING TO VOLUNTARILY SUPPORT OTHERS ENDURING LOSS

Connie has worked as an Early Childhood Educator in the Fraser Salish region for over two decades. She operates a bus equipped with cultural activities, arts and crafts, and games to engage children with enriching experiences, bringing early childhood education directly to families across the region.

Connie possesses a remarkable gift for listening and building empathy. This has made her a trusted confidante for many in her community. Motivated by her own unexpected and tragic loss of a parent, Connie has spent years helping friends and family navigate the complexities of sudden death, encouraging others to plan for their end-of-life journey.

She chose to participate in the IELOG training to build upon her existing skills, knowledge, and expertise and to enhance the services she has voluntarily provided for many years.

#### Connecting With Like-Minded Individuals and Expanding Her Skillset

Connie attended the IELOG training program in 2023 and found the experience profoundly rewarding. She found the in-person training sessions provided an enabling environment grounded in safety, respect, and relational connection where everyone could open up about their personal experiences. She appreciated the authenticity and vulnerability that emerged in these sessions, learning the importance of being present and supportive without always needing to have the perfect response.

The training also highlighted for Connie the significance of ongoing learning, inspiring her to supplement her training with additional courses focused on overcoming trauma.

#### Supporting Services and Community Connections

Connie estimates that she has provided end-of-life support and guidance to over many individuals and their families, and that the true impact is likely far greater, as individuals she has helped have gone on to support others within their communities.

Her end-of-life support services are often sought out through word-of-mouth, and individuals approach her across the multiple communities she serves as an Early Childhood Educator.

Connie's non-judgemental approach and deep humility allow individuals to discuss sensitive issues with her. Feeling a sense of calm and peace following their interactions with her, many community members express their gratitude through gestures of affection, like hugging her, to show that they felt heard and respected. One individual, who had lost his mother, shared with Connie that she was the first person who truly listened to him.

Connie's work also involves understanding and respecting the cultural practices of different communities. Acknowledging that each community has its own ways of dealing with end-of-life matters, she strives to support them in their preferred cultural practices.

## 4.4 COMPLEMENTING EXISTING INDIGENOUS END-OF-LIFE SERVICES AND SUPPORTS

**IEOLG services complement other FNHA-supported or delivered programs and services for First Nations individuals and families in BC navigating the end-of-life journey. The flexible and tailored nature of the services allows guides to fill gaps and serve as a liaison and navigator.**

The FNHA delivers a range of programming that supports First Nations individuals and families in BC navigating the end-of-life journey. These include direct supports by the regional nursing and mental health and wellness teams, development of policies, fund administration for community programming, and development of online materials and resources on topics including advance care planning,<sup>7</sup> the end-of-life journey<sup>8</sup> and medical assistance in dying.<sup>9</sup> The FNHA recently developed the Healing Indigenous Hearts program,<sup>10</sup> which is delivered regionally and helps communities establish peer support groups for families experiencing grief and loss related to substance use.

According to staff of other FNHA programs, the IEOLG program complements, rather than duplicates, other end-of-life, grief and healing services, particularly because of the range and flexibility of services provided by the guides. Guides fill a critical gap in existing community-based health care services, which are often understaffed due to health care provider shortages. The IEOLG program supports all community members facing the end of life and grieving family members, whereas some other programming, such as Healing Indigenous Hearts is specifically targeted to families who experience unexpected death due to the ongoing toxic drug crisis.



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<sup>7</sup>Advance Care Planning.

Available from: [www.fnha.ca/what-we-do/healthy-living/advance-care-planning](http://www.fnha.ca/what-we-do/healthy-living/advance-care-planning).

<sup>8</sup>End of Life Journey.

Available from: [www.fnha.ca/what-we-do/healthy-living/end-of-life-journey](http://www.fnha.ca/what-we-do/healthy-living/end-of-life-journey).

<sup>9</sup>Medical Assistance in Dying (MAID).

Available from: [www.fnha.ca/what-we-do/healthy-living/end-of-life-journey/medical-assistance-in-dying](http://www.fnha.ca/what-we-do/healthy-living/end-of-life-journey/medical-assistance-in-dying).

<sup>10</sup>FNHA Healing Indigenous Hearts program.

Available from: [www.fnha.ca/Documents/Healing-Indigenous-Hearts.pdf](http://www.fnha.ca/Documents/Healing-Indigenous-Hearts.pdf).

## 5. LEARNINGS AND OPPORTUNITIES TO ENHANCE END-OF-LIFE CARE FOR FIRST NATIONS IN BC

### 5.1 IEOLG PROGRAM: INCREASING AWARENESS OF AVAILABLE SERVICES

**Increase awareness of guide services among FNHA staff, community leadership, and members to improve service uptake and referrals.**

Despite the FNHA's promotion efforts, the awareness of the services offered by guides remains low among FNHA regional staff, community leadership and community members. This has resulted in community members not seeking services from guides, and guides not receiving referrals. About half of the surveyed Health Directors and interviewed regional staff members were unaware of the IEOLG services, and half of surveyed guides identified this lack of awareness as a critical barrier for practising their skills.

There is an opportunity to raise awareness of the services among other FNHA teams who work closely with First Nations communities and community members (e.g., nursing and mental health wellness teams, and First Nations Primary Care Centres).

Suggestions from guides included:

- ◆ Creating a centrally managed, publicly available and searchable repository of guides practising in the province, similar to the current list of mental health providers available on the FNHA website;<sup>11</sup>
- ◆ Creating digital and print resources for health care providers that include a description of the guide's function and services, as well as a link to the central repository of practising guides, and distributing them to local health care spaces (e.g., long-term care centres, hospices, primary care clinics, Aboriginal and Indigenous patient navigators and palliative care units in hospitals); and

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<sup>11</sup>Registered Mental Health Providers.

Available from: [www.fnha.ca/benefits/mental-health-providers](http://www.fnha.ca/benefits/mental-health-providers).

- ◆ Creating posters and brochures targeted to community members promoting guides' services and how to contact them, displaying the information in community health spaces, and including them in regional and community newsletters.



## 5.2 IEOLG PROGRAM: ENHANCING CULTURAL LEARNING OPPORTUNITIES

Increase opportunities for guides to learn about cultural teachings in grief and healing support, which can be further tailored to Nation, family and sub-regional priorities, traditions and cultural practices.

The majority of surveyed guides expressed a strong interest in expanding their understanding of how to provide grief and healing support, drawing on both a western palliative care model and Indigenous healing practices. They emphasized the importance of learning from cultural, ceremonial and spiritual teachings related to the end-of-life journey and suggested creating more opportunities to engage with Knowledge Keepers who have in-depth understanding in this area.

There is also an opportunity for guides to collaborate with local Elders and Knowledge Keepers to enrich their practice and continue incorporating local beliefs, customs and practices related to the end-of-life journey and grief support. Health Directors and surveyed guides also suggested working with communities and regions to develop terminology that reflects First Nations values and traditions, integrating them into future iterations of the IEOLG curriculum.



**“Adapting the training to meet the specific cultural practices of the regions could significantly enhance its effectiveness. This could include incorporating local traditions, beliefs and customs related to end-of-life care and grief into the curriculum. Collaborating with local Elders, healers and community leaders could provide valuable insights into how to tailor the training to better resonate with participants and the communities they serve.”**

**– FNHA regional staff member**

### 5.3 IEOLG PROGRAM: PROVIDING POST-TRAINING SUPPORT FOR GUIDES

Provide ongoing post-training learning opportunities, such as a community of practice, to bolster guides' confidence and skillsets.

Many guides shared that it is crucial that ongoing learning opportunities be provided to support them in delivering end-of-life services. Guides suggested some approaches for post-training learning, which include ongoing learning sessions, an online resource platform and distributing a newsletter. These pathways would enable guides to access and be updated about newly added tools, resources and wise practices, such as advance care planning, end-of-life traditions, cancer care, and grief and trauma support. Guides also emphasized the importance of highlighting self-care, given the emotional nature of the work, whereby program provisions include resources and aids that support guide resilience and capacity for care. Books written by Barbara Karnes were also recommended as a helpful resource for guides.



Similar programs in other jurisdictions confirmed that regular training opportunities are critical to encourage guides to continue offering services. For example, the Palliative Care for Front-line Workers in Indigenous Communities program, implemented by Lakehead University, offers a range of ongoing learning opportunities, such as workshops and webinars.<sup>12</sup>

**“There is so much to learn in a limited number of days. Ongoing gatherings with information are vital. I haven't heard from other guides; I'd love to hear how they are doing. I feel this program should be ongoing, evolving to keep the training, skills and knowledge sharp.”**

**– Guide**

Surveyed guides recommended that the FNHA could organize a monthly online community of practice and annual in-person gatherings to support connections among guides, promote lateral knowledge sharing and increase confidence.

**“The training was beyond my expectations; however, there did not seem to be any follow-up support or touch base . . . what do we as guides do with this newfound knowledge? We need hands-on, one-to-one support, with interactive practices, assignments – make it longer and drawn out over weeks or months. This was too short to feel qualified to support people and families in one of the most impactful times of life.”**

**– Guide**

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<sup>12</sup>Lakehead University, Indigenous Peoples' Health and Aging.  
Available from: [cerah.lakeheadu.ca/resources/indigenous-health/](https://cerah.lakeheadu.ca/resources/indigenous-health/).

## 5.4 FNHA: STRENGTHENING COMMUNITY CAPACITY AND EXPERTISE

The opportunities and knowledge offered through programs like the IEOLG program can be expanded to build community capacity and expertise around end of life. Communities suggest a one-time special purpose grant or contribution agreement could support Nations or communities to build end-of-life expertise and capacity through development of a tailored guide or informational resources, a funded navigator or guide position, and end-of-life planning workshops. There is also potential for the FNHA to provide surge capacity support following crises with loss of life.

Chiefs and Health Directors suggest there is opportunity to expand programs like the IEOLG training program to a special purpose grant and contribution agreement funded initiative to support Nations and communities who are interested in building end-of-life expertise and capacity. Suggestions for expanding the program scope included:

- ◆ Providing support to participating Nations, families and sub-regions to develop a resource guide tailored to their community's specific context, services and supports. This could be a PDF booklet, similar to the Province of BC's After a Death Checklist<sup>13</sup> and FNHA and BC Cancer's booklet, Preparing for the Journey: Wholistic end-of-life care for First Nations people living in BC,<sup>14</sup> with a modifiable section for guides and community health leadership to tailor to local providers, services and supports.
- ◆ Continue supporting community-led end-of-life preparedness initiatives for members on topics such as preparing a will and advance care planning.
- ◆ Providing surge capacity end-of-life, grief and healing support, potentially through FNHA Regional Mental Health and Wellness Teams, when communities experience sudden deaths associated with crises.

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<sup>13</sup>After a Death Checklist.

Available from: [www2.gov.bc.ca/assets/gov/birth-adoption-death-marriage-and-divorce/deaths/after-a-death/after\\_death\\_checklist.pdf](http://www2.gov.bc.ca/assets/gov/birth-adoption-death-marriage-and-divorce/deaths/after-a-death/after_death_checklist.pdf).

<sup>14</sup>Preparing for the Journey.

Available from: [www.fnha.ca/Documents/FNHA-Preparing-for-the-Journey-Booklet.pdf](http://www.fnha.ca/Documents/FNHA-Preparing-for-the-Journey-Booklet.pdf).

## SPOTLIGHT:

In one First Nations community in the Fraser Salish Region, community leaders have developed guidebooks for members instructing them on what to do when a death occurs in their family. The guidelines cover issues such as planning for the end of life, organizing a funeral and seeking help. The leadership has also assigned a staff member to assist members during such difficult times and help them follow the guidelines.

"I would love to see this work be paid so that we can afford to be of more service to the greater community. It can be a great commitment of time to be in support of a death and I can't always afford it, unfortunately."

- Guide

"Our community is at a population of 2,200 – the more guides, the better. We've been having passings weekly, sometimes two or three a week, and we don't want to burn them out."

- Health Director

## 5.5 PROVINCIAL AND REGIONAL PARTNERS: HARDWIRING CULTURAL SAFETY AND HUMILITY IN SERVICES DELIVERED TO FIRST NATIONS

Provincial and regional partners need to improve the cultural understanding of their staff providing end-of-life services to First Nations and recognize First Nations customs and traditions in provincial legislation and policies regarding death.

Staff members working in hospices or palliative care units in hospitals often lack adequate understanding of Indigenous values, culture and needs. Regional health authorities need to improve the cultural understanding of their staff serving First Nations, as part of their commitments stated in the BC Tripartite Framework Agreement on First Nations Health Governance,<sup>15</sup> the Truth and Reconciliation Commission's Call to Action, and the In Plain Sight Report,<sup>16</sup> and to meet the British Columbia Cultural Safety and Humility Standard. The FNHA can support the regional health authorities and other health system partners, such as the BC Coroners Service, by providing specific training cohorts for health provider staff, as discussed in Section 5.1.

Similarly, and in line with the *Declaration on the Rights of Indigenous Peoples Act*, the Province needs to recognize First Nations traditions and customs relating to death and burial in legislation and policies. For example, in many First Nations communities in BC, it is custom to organize the burial and related ceremony within four days following a death; however, current coroner services and provincially legislated procedures often result in much longer wait times.

**“Currently, communities need to navigate BC’s jurisdiction around death and burials which often contradict First Nations ways of knowing and being.”**

**– Health Director**

### SPOTLIGHT:

The Interior Health Hospice Palliative Care Program includes Indigenous cultural practices for patients from First Nations communities. Some of the services provided include cultural traditions such as drumming, singing and smudging.

<sup>15</sup>British Columbia Tripartite Agreement on First Nation Health Governance (2011).

Available from: [www.fnha.ca/Documents/framework-accord-cadre.pdf](http://www.fnha.ca/Documents/framework-accord-cadre.pdf).

<sup>16</sup>Addressing Racism in BC.

Available from: [engage.gov.bc.ca/addressingracism/](http://engage.gov.bc.ca/addressingracism/).

## 5.6 TRIPARTITE PARTNERS: BRINGING CARE CLOSER TO HOME

The FNHA should continue its collaborative work with Tripartite Partners to bring end-of-life care closer to community.

In 2022, the FNHA's Wholistic Integrated Continuum of Care (WICC) engaged with First Nations communities to better understand future care needs and priorities across the lifespan.<sup>17</sup> These findings were validated across the province in 2023.<sup>18</sup> More information about what was heard at the engagements and the path forward can be found on the WICC team's web page.<sup>19</sup> The FNHA and the WICC team will continue working with the BC Ministry of Health and Indigenous Services Canada to build the structures and systems needed for bringing services closer to home.



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<sup>17</sup>Engagement Report 2022. Care Close to Home.

Available from: [www.fnha.ca/Documents/FNHA-Engagement-Report-2022.pdf](http://www.fnha.ca/Documents/FNHA-Engagement-Report-2022.pdf).

<sup>18</sup>Engagement and Validation Report 2023. Bringing Care Closer to Home. Phase Two.

Available from: [www.fnha.ca/Documents/FNHA-Engagement-and-Validation-Report-Phase-Two-2023.pdf](http://www.fnha.ca/Documents/FNHA-Engagement-and-Validation-Report-Phase-Two-2023.pdf).

<sup>19</sup>FNHA Wholistic Integrated Continuum of Care.

Available from: [www.fnha.ca/what-we-do/wholistic-integrated-continuum-of-care](http://www.fnha.ca/what-we-do/wholistic-integrated-continuum-of-care).



## 6. CONCLUSION

From 2019 to 2023, the IEOLG program trained 455 participants representing 163 First Nations communities. Trainees acquired a wide range of skills and knowledge regarding Indigenous perspectives on the end-of-life process, grief and healing. Three-quarters of the individuals who completed the program have practised their skills in their communities. Training participants assisted individuals and families by sharing Indigenous perspectives on end-of-life processes, grief and healing; facilitated family discussions around the end of life and grief; helped with care planning; and advocated on behalf of clients.

Services provided by the guides have generated a range of positive impacts, including bringing peace and comfort to patients and their families, supporting individuals' final wishes at the end of their life, supporting families to prepare for, and heal from, the loss of loved ones, connecting families to appropriate resources in their communities, and supporting advocacy and system navigation. Furthermore, the program has contributed to the increased availability and use of culturally safe end-of-life services for First Nations communities in BC.



Despite progress, the number of community members spending their final days outside their community is still very high. More resources, time and effort are required to enable all First Nations people the option of transitioning to the Spirit World within their communities with dignity and in ways suitable to their wishes.

While there are opportunities for improvement, the overall design of the delivery structure of the IEOLG program is effective. Training participants reported a high level of satisfaction with the course. Particular strengths associated with the existing curriculum design include the skills and qualifications of the staff and facilitators, the incorporation of cultural and traditional aspects into the curriculum, the creation of a safe environment for sharing personal stories and expressing emotions during sessions, and the interactive nature of the discussions.

In-person delivery of the training is more effective, as it encourages human interactions and creates a safe space for learning. An online delivery option is also necessary, as it is more accessible for those who live in remote areas and those serving immunocompromised clients and seeking to reduce potential exposure to viruses. The IEOLG program is well-aligned with other FNHA programs and services, and is complementary to existing end-of-life services and programming available in First Nations communities.



## 7. THE PATH FORWARD

### 7.1 INDIGENOUS END-OF-LIFE GUIDE EXPANSION PROJECT

The IEOLG program is entering a new phase of growth and is expanding along an alternate capacity. In this phase, the program will not offer training for new guides; instead, it will focus on further supporting and enhancing the capacity of the existing guide community. This will be achieved through the development of tools and resources that improve the accessibility of supports, and the promotion of enabling environments that foster engagement and knowledge sharing across system partners.

The Indigenous End-of-Life Guide Expansion Project will be implemented in two phases:



#### **Phase 1: Resource Development and Accessibility (August 2025 to March 2026)**

Phase 1 of the expansion project will focus on the collaborative creation of tools and resources, along with the development of a regional interactive map of current guides.

The FNHA will work closely with current guides to co-develop practical tools and resources that support their work in communities. Additionally, a digital interactive map will be created to help individuals and families locate guides and access culturally safe end-of-life support services across regions, which aligns with the opportunity identified in 5.1.

#### **Phase 2: Curriculum Expansion and System Integration (April 2026 to March 2027)**

Phase 2 will focus on enhancing the IEOLG curriculum and building communities of practice to strengthen connections and promote lateral knowledge exchange.

In collaboration with First Nations health leads, current guides and FNHA teams, the curriculum will be updated to reflect insights from the evaluation. This includes integrating five opportunities identified above:

- Updating training design and delivery
- Providing post-training support
- Strengthening community capacity and expertise
- Embedding cultural safety and humility into all services
- Bringing care closer to home

In response to community and Elder feedback, the project will also facilitate joint learning experiences between First Nations health teams and regional health authority partners. These opportunities aim to foster mutual understanding, relationship-building, and collaborative care.



First Nations Health Authority  
Health through wellness

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