BC Centre for
Palliative Care

Facilitating Equitable Access to Palliative and End-Of-Life Care for Underserved Populations in British Columbia: Knowledge Exchange Series (2025)

Insights Specific to:

People Living with a
Life-Limiting Illness and
Neurodevelopmental Disabilities

How to Cite this Document

BC Centre for Palliative Care. (2025). Facilitating Equitable Access to Palliative and End-of-Life Care for Underserved Populations in British Columbia: Knowledge Exchange Series (2025). Insights specific to: People Living with a Life-limiting Illness and Neurodevelopmental Disabilities.

For More Information

For more information about this report, please communicate with:

Rachel Carter, PhD
Director of Research
BC Centre for Palliative Care

Email: rcarter@bc-cpc.ca

Eman Hassan MD, MPH
Executive Director
BC Centre for Palliative Care

Email: ehassan@bc-cpc.ca

Knowledge Exchange Overview

In Spring 2025, the BC Centre for Palliative Care on behalf of the BC Palliative Care Research Collaborative hosted a three-part virtual **Knowledge Exchange Series** on *facilitating equitable access to palliative and end-of-life care for underserved populations in BC*.

Shaped by research, expert insights, and lived experiences, the series aimed to advance an equity-informed approach to palliative care by sharing stories, highlighting promising practices, strengthening connections between health and community systems, and identifying future directions for policy, practice, and research.

Discussions and activities focused on twelve underserved population groups with limited access to essential palliative and end-of life care services.

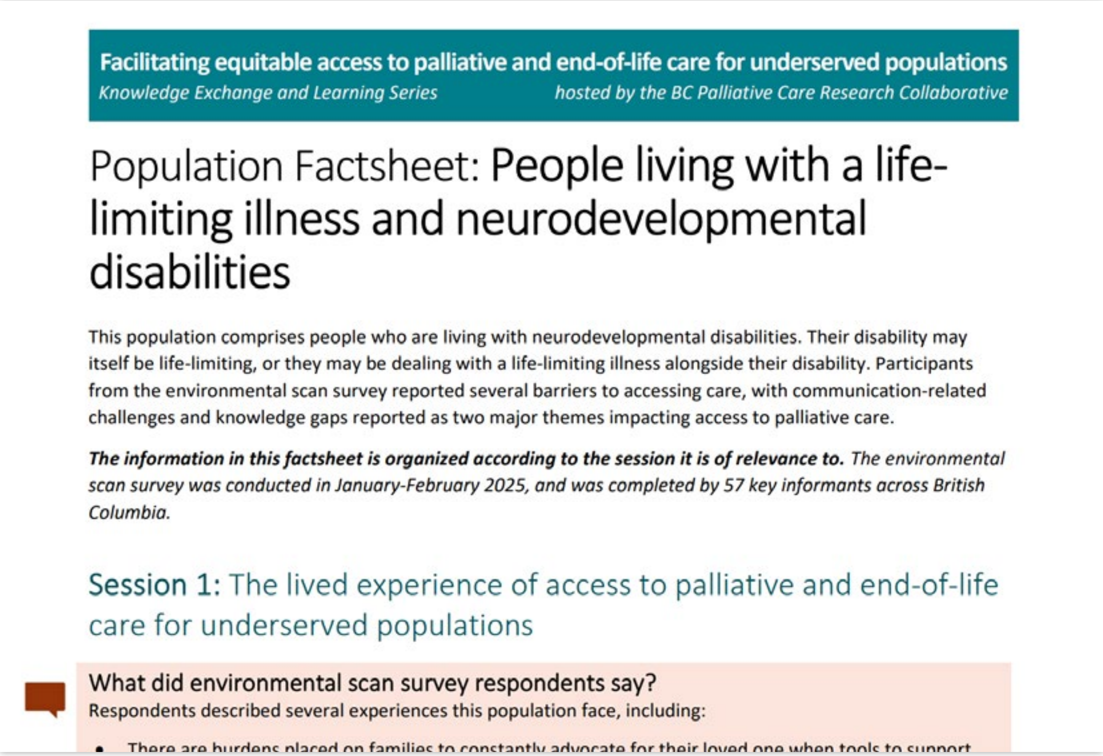
Read the full Summary Report here.

Insights Specific to People Living with a Life-Limiting Illness and Neurodevelopmental Disabilities

Insights from the Literature and Key Informants

To inform discussions about **people living with a life-limiting illness and neurodevelopmental disabilities** during the Knowledge Exchange sessions, a population fact sheet was developed. The fact sheet summarizes key themes from a literature review and insights gathered from key informants through an online survey—highlighting experiences, opportunities, facilitators, and barriers to care.

View the population fact sheet here. A preview is shown below.



Facilitating equitable access to palliative and end-of-life care for underserved populations
Knowledge Exchange and Learning Series *hosted by the BC Palliative Care Research Collaborative*

Population Factsheet: People living with a life-limiting illness and neurodevelopmental disabilities

This population comprises people who are living with neurodevelopmental disabilities. Their disability may itself be life-limiting, or they may be dealing with a life-limiting illness alongside their disability. Participants from the environmental scan survey reported several barriers to accessing care, with communication-related challenges and knowledge gaps reported as two major themes impacting access to palliative care.

The information in this factsheet is organized according to the session it is of relevance to. *The environmental scan survey was conducted in January-February 2025, and was completed by 57 key informants across British Columbia.*

Session 1: The lived experience of access to palliative and end-of-life care for underserved populations

What did environmental scan survey respondents say?
Respondents described several experiences this population face, including:

- There are burdens placed on families to constantly advocate for their loved one when tools to support

Insights from the Knowledge Exchange Series

Key barriers, potential solutions and recommended actions that emerged from discussions on improving palliative and end-of-life care access for *people living with a life-limiting illness and neurodevelopmental disabilities.*

Insights Specific to People Living with a Life-limiting Illness and Neurodevelopmental Disabilities

Barriers

- **Assumptions about capacity:** Patients may be misunderstood as being unable to make decisions, especially when family and patient wishes conflict.
- **Siloed systems:** Disability and healthcare providers lack access to each other's information.
- **Gaps in care:** Group homes don't always ensure adequate access to medical care; families often don't know where to go for help.
- **Limited staff education:** Staff lack training in neurodevelopmental disabilities, such as how to properly care for these patients and what kinds of community supports are available for them.
- **Low staffing capacity:** Care planning is complex, long-term, and time-intensive.
- **Bias in care:** People with disabilities may be less prioritized for urgent or medical care because of assumptions that their quality of life is lower.
- **Inadequate tools/resources:** Existing clinical tools are not well-suited for this population's needs. Community Living BC also finds that relevant services, resources, and people to contact change often, which makes it difficult to maintain an up-to-date list of resources.

Solutions

- **Create aging protocols:** Develop clear care plans for adults with complex needs as they age.
- **Add navigators:** Provide local/regional support to help families navigate the system.
- **Improve information-sharing:** Ensure care teams can access up-to-date patient information across settings.
- **Adopt annual knowledge-sharing:** Ongoing (annual) person-to-person education between organizations keeps relationships alive and information/education flowing between organizations.
- **Make charting person-centred:** Using a storytelling approach—where patients' experiences, values, and goals are included—can help improve communication between providers and patients.
- **Hire HSCL nurse:** A dedicated Health Services for Community Living nurse can coordinate care for this population.
- **Centralize resources:** Combine services in one accessible location (for example, the Foundry model).

Recommended Action

There's a lot of confusion in the healthcare and community systems about who is responsible for what, and where the gaps in support are. By clearly defining roles/responsibilities and creating shared protocols, we can make it easier for families, healthcare providers, and community organizations to work together and improve access to appropriate care. Person-centred team-based care is a key way to address the disconnect for individuals between the hospice/palliative care and the disability care systems.

Insights from the Knowledge Exchange Series

After the Knowledge Exchange Series, participants completed a survey to prioritize the most important research questions and promising solutions for each underserved population.

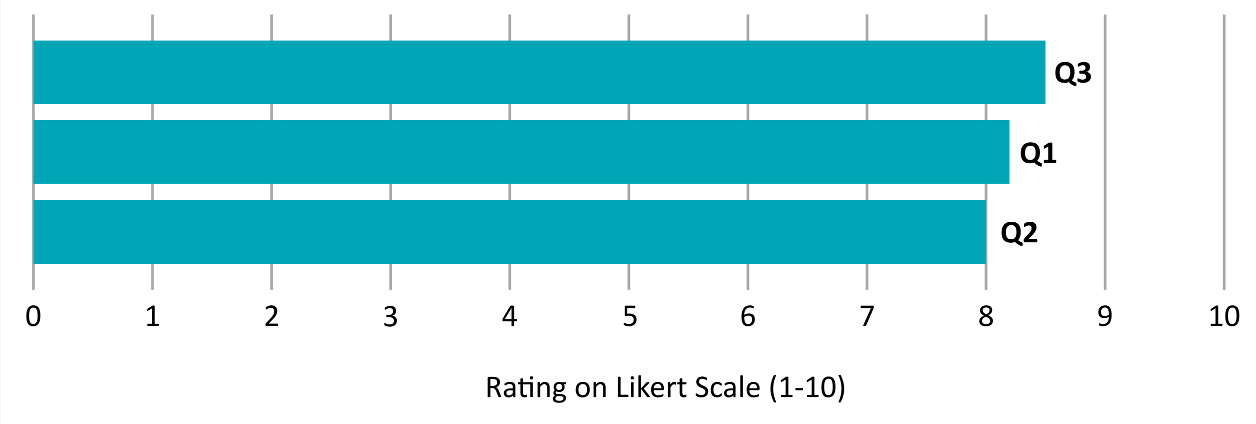
Top three rated research questions and promising solutions for *people living with a life-limiting illness and neurodevelopmental disabilities.*

	Top 3 Questions to Answer	Top 3 Solutions to Consider
1	**System/Program Planning** How can we strengthen the referral system to prevent service gaps, particularly during critical transitions such as from pediatric to adult care?	**System/Program Planning** People need support in navigating and knowing what is possible, such as available services.
2	**Research** What ethical challenges arise around assent and consent in palliative care for people with diminished capacity, and how can these be navigated responsibly?	**Practice/Care** Update the protocol clarifying when healthcare and Community Living BC are responsible, emphasizing collaboration over handoffs by outlining each partner's contributions.
3	**Practice/Care** How can we integrate disability-informed practices into all types and stages of care?	**Education/Training** Normalize advance care planning conversations through a national campaign or leveraging some clever tools to enable regular conversation.

The average importance rating for each priority research question related to *people living with a life-limiting illness and neurodevelopmental disabilities*.

Priority Research Questions: What do you want to know or solve? *(Session 3 Breakout 1)*

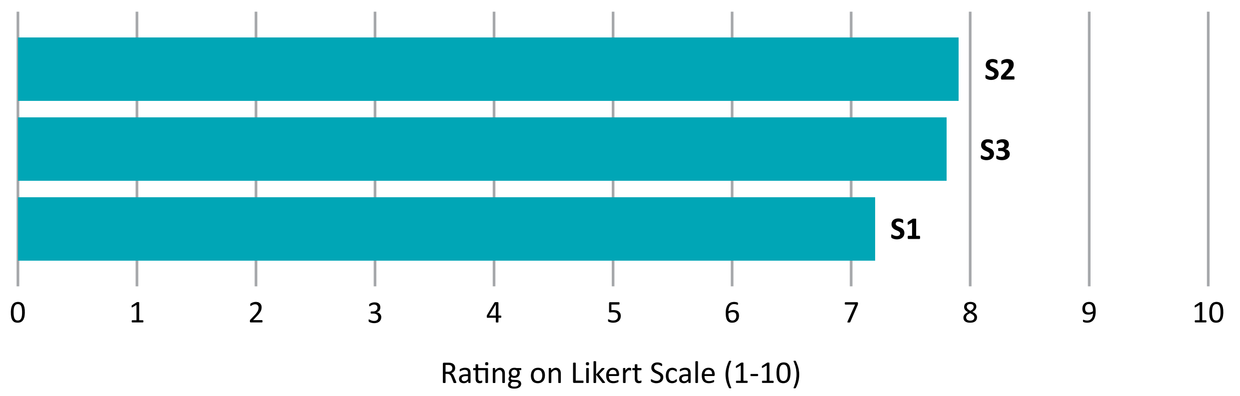
	Question	Average Rating
1	Research: What are the ethical challenges surrounding assent and consent in palliative care for individuals with diminished capacity or complex circumstances, and how can these be navigated responsibly? Are there any legal frameworks guiding end-of-life decisions for adults with neurodevelopmental disabilities?	**8.2**
2	Practice/care: How can we integrate disability-informed practices (for example, accessibility accommodations, communication supports, etc) are integrated into all types and stages of care? Are there any care models or interventions that exist that are tailored towards people with neurodevelopmental conditions?	**8.0**
3	System/program planning: How can we strengthen the referral system to prevent service gaps, particularly during critical transitions such as from pediatric to adult care, to ensure continuity and equity in support? *(Highest Rated)*	**8.5**



The average importance rating for each priority promising solution related to *people living with a life-limiting illness and neurodevelopmental disabilities*.

Priority Research Solutions: What can be done right now and by who? *(Session 3 Breakout 2)*

	Solution	Average Rating
1	Education: Normalized advance care planning conversations through either a national campaign or through leveraging some clever tools to enable regular conversation. For example, there is an Australian card game that helps engage people in these conversations.	**7.2**
2	System/program planning: Support people in navigating and knowing what is possible, such as what services are available. *(Highest Rated)*	**7.9**
3	Practice/care: Update the protocol for when healthcare is responsible and when Community Living BC (CLBC) is responsible. Perhaps this protocol can include information about what each of these players can contribute and bring to the table collaboratively, rather than making it a handoff between organizations.	**7.8**



For similar insights on other underserved populations, visit the BC Centre for Palliative Care website here.

BC Centre for Palliative Care

Advancing palliative care through best practices, innovation and collaboration.

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