INTELLECTUAL & DEVELOPMENTAL DISABILITIES
PALLIATIVE CARE NETWORK

INTELLECTUAL and DEVELOPMENTAL DISABILITY PALLIATIVE CARE RESOURCE GUIDE and TOOLKIT

A Knowledge-to-Action Guide for Developmental Services, Healthcare, and Palliative Care Providers

Enabling Equitable Access to Quality Palliative Care for People with Intellectual and Developmental Disabilities, their Families, and Provider Team(s)

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Dedicated to the memory of Claire Staniforth, Team Lead, Transitional Services Facilitator, Plus 45 Clinic, Surrey Place IDD Palliative Care Network Co-Chair (2020 - 2022), for her vision, passion, leadership, and tireless advocacy to advance high quality palliative care for People with Intellectual and Developmental Disabilities.

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Executive Summary

People with intellectual and developmental disability (PWIDD), many with complex needs, lack equitable access to high quality palliative care, including providers with confidence and competency in Intellectual and Developmental Disability (IDD) focused palliative care.

In January 2021, the Intellectual and Developmental Disability Palliative Care Network (IDD PCN) inaugural meeting was held. Forty representatives from across Ontario from Developmental Services (DS), palliative and healthcare sector members came together with an aim to improve palliative care for people living with intellectual and developmental disability (PWIDD); capacity build across sectors; with the initial step being development of the ***Intellectual and Developmental Disability (IDD) Palliative Care Resource Guide and Toolkit, A Knowledge-to-Action Guide for Developmental Services, Healthcare and Palliative Care Providers for Ontario***. Following adult palliative care gold standards, the IDD Palliative Care Toolkit is intended to guide cross sector knowledge and application in providing a palliative care approach for adult PWIDD by serving as the IDD supplement to the *Ontario Health Palliative Care Toolkit*[i] produced by the Ontario Palliative Care Network (OPCN).

OUR VISION

The vision of the IDD PCN is that all people with intellectual and developmental disabilities and their *Circle of Support* have equitable access to high quality palliative care. This incorporates respect for personhood, dignity, trauma-informed approaches, and early identification of palliative care needs. Palliative care for PWIDD is provided by an effective, responsive, and collaborative care team that includes developmental services at the core along with healthcare and palliative care providers.

OUR GUIDING PRINCIPLES

The guiding principles of the IDD PCN are influenced by the self-determination and respect for personhood of the person with IDD. The principles used to guide the development of this Palliative Care IDD Toolkit align with the guiding principles of the Framework on Palliative Care in Canada[ii] and the Ontario Palliative Care Network's Model of Care for Adults in Community Settings[iii] but are modified to

focus on the distinct needs of PWIDD. A comparison table of these guiding principles can be found in Appendix A.

- **Palliative care is person-centred care with focus on self-determination of the individual with IDD.** This entails respect for personhood and for the person's dignity, recognizes the importance of relational autonomy, and is expressed through practices such as supported decision-making.

- **Palliative Care incorporates not only care for the person with IDD but also extends to their *Circle of Support*.** Developmental Services Ontario defines circle of support as a group of people who come together to help a person with a developmental disability think about and take action toward their interests, goals, and needs.

- **Palliative care is integrated into developmental service care delivery, (across care settings and between care providers).**

- **Access to palliative care is equitable, inclusive, and addresses healthcare access inequities for PWIDD.** This includes supporting palliative care in the person's home environment (when possible) or place of choice and using accessible and adaptive communication (including grief and bereavement resources for PWIDD and those that care for them/about them).

- **Palliative care services are valued, understood comprehensively, collaboratively, and adequately resourced for PWIDD.** Historically, PWIDD are underserviced in palliative care; there is a need to support capacity building of providers and development of sustainable infrastructure. Interdisciplinary collaborative team members, which includes *DS* sector and healthcare providers, have necessary competencies to care for PWIDD supported by reciprocal learning between healthcare and DS.

- **Palliative care is high quality and evidence informed.** Excellence in palliative care is inclusive of, but not limited to, holistic, trauma-informed, culturally safe, and timely care. Due to limited research with PWIDD and palliative care, traditional evidence-based practice is informed by "good practice." "Good practice" has evolved out of clinical and organizational practices, as well as the lived experience of PWIDD and those who support them.

- **Palliative care is a shared responsibility.** The measure of a good society is how we treat our most vulnerable, such as PWIDD. Quality palliative care entails both caring for and caring about PWIDD and their *Circle of Support*. Striving to be a good society requires that all members, across government, *DS* sector, healthcare, and the public at large, work together to promote and provide palliative care for this population.

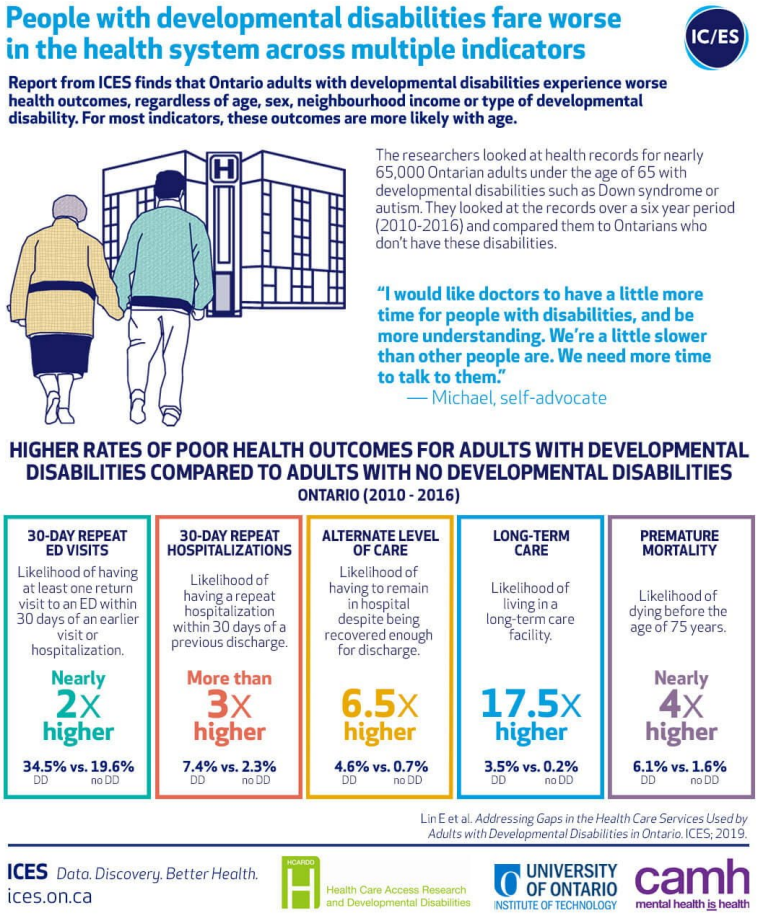
- **Palliative Care for PWIDD is guided by ethical principles and values, including Ethics of Care**. This acknowledges the importance of the reciprocal relationship between persons, their *Circle of Support*, the DS sector, and healthcare providers. Ethics of care values the voice of the person and maximizes participation in their own decision making.

INTRODUCTION

The statistics illustrated in the Figure 1. Infographic is a jarring. People with intellectual and developmental disability (PWIDD) experience poor health outcomes, regardless of age, sex, neighbourhood income or type of developmental disability. Behind each of the statistics is a person who would benefit from a palliative approach to care.

Figure 1.

ICES Infographic – People with Developmental Disabilities fare worse in the health system across multiple indicators[iv]



Ontario's provincial palliative care strategy would benefit from an Intellectual and Developmental Disability (IDD) inclusion, to ensure PWIDD are living and dying with equitable access to proactive, reliable, and responsive palliative approaches to care. The response was the development of this **Intellectual and Developmental Disability (IDD) Palliative Care Resource Guide and Toolkit** for Ontario.

The IDD Palliative toolkit aims to provide a knowledge-to-action framework for cross-sector capacity building, strengthening confidence and competency in IDD-specific palliative care.

LEVERAGING OPPORTUNITIES

Policy directions resulting in financial constraints from funding authorities have led to attempts to do more with less resources. While the difficulty of allocating limited human resources is true of the general population, in this fragile and vulnerable population, the negative consequences of these challenges are amplified.

The World Health Organization's (WHO), World Report on Disability[v] advocates for a 'mainstream' approach where possible, recognizing that disability-specific services will also be necessary.
The recommendations are:

- Seek opportunities to ally with other initiatives for the general population.
- Advance health and reduce health disparities of PWIDD.
- Strategically leverage and emphasize inclusion in cross-disability approaches and mainstream service where possible.
- Educate decision makers.
- Draw more attention to social determinants and a life-course model.

Aligning palliative care for PWIDD with the work of OPCN's Ontario Palliative Care Action Plan[vi] has the potential to reduce palliative care disparities for PWIDD. It leverages cross-disability approaches, educates decision makers, and includes attention to social determinants of health; thereby, standardizing the combined efforts of Developmental Service providers, healthcare providers, and palliative specialists.[vii]

BACKGROUND

Intellectual & Developmental Disability (IDD) – Definition

Under Ontario's *Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act*[viii] developmental disability is an umbrella term for different disabilities that involve the person having, "prescribed significant limitations in cognitive functioning and adaptive functioning and those limitations, (a) originated before the person reached 18 years of age; (b) are likely to be life-long in nature; and (c) affect areas of major life activity, such as personal care, language skills or learning abilities, the capacity to live independently as an adult or any other prescribed activity" (Sec. 3.1).[viii]

As defined in the Act, cognitive functioning refers to, "a person's intellectual capacity, including the capacity to reason, organize, plan, make judgments and identify consequences"(Sec. 3.2).[vii] Adaptive functioning speaks to, "a person's capacity to gain personal independence, based on the person's ability to learn and apply conceptual, social and practical skills in everyday life" (Sec. 3.2).[vii] Conditions such as intellectual disability, autism, Down syndrome and fetal alcohol syndrome would all fit under this umbrella term.

Developmental disabilities can be genetic in origin (e.g., fragile X syndrome or Williams syndrome) or can be caused by illness or injury prenatally (e.g., maternal rubella or maternal alcohol consumption) or in early childhood (e.g., meningitis); in some cases, their cause is unknown. In Ontario, medical disabilities, such as cerebral palsy or epilepsy, and psychiatric disorders are not considered developmental disabilities unless they meet all the criteria of the above definition.[ix]

IDD Common Etiologies

Genetic	Global	Pre/Post Natal Injury
Deletion Syndrome(s) e.g. Fragile X; Prader-Willi; Angelman; Rhett Syndrome; 22q11.2 Deletion Syndrome	Global Developmental Delay (unknown etiology)	Fetal Alcohol Syndrome (FAS)
Down's Syndrome	Autism Spectrum Disorder	Cerebral Palsy (if meets DSO criteria)
Smith Magenis Syndrome		Maternal rubella
Williams Syndrome		Neurologic sequelae of early childhood meningitis

Health Watch Tables, Developmental Disabilities Primary Care Initiative (2011), Surrey Place, Toronto

IDD Prevalence

Estimated 2% – 4 % prevalence in Ontario and Canada (9 PWIDD/1,000 population.[x]

Data is widely considered an underestimate due to challenges of: [x, xi, xii]

- Data depending heavily on care seeking behaviours.
- Unlinked data between Ministry of Children, Community and Social Services; Ministry of Health and Ministry of Long-term Care; Ministry of Education.
- Unknown numbers are in Long-Term Care Homes (LTCH).
- Unknown numbers rurally, estimated as 40% of PWIDD residing in rural areas.
- Unknown numbers of PWIDD in Indigenous (FNIM) and Newcomer populations.
- Unknown numbers without formal diagnosis.
- Data deficiencies and integrity issues compound the invisibility of PWIDD and their carers, creating issues of policy and service planning based on known underestimated numbers. This has impeded priority attention for resource allocation and services.

Historical Context

Many PWIDD lived in provincial institutions prior to the 1970s. The last three remaining Ontario Institutions/Regional Centres closed in March 2009[xiii]. Issues of pre-mature death and trauma experienced in institutional care resonates to this day.[xiv, xv, xvi, xvii]

- Many endured unethical and abusive actions by the guidance of the "professionals of the day, healthcare providers," which resulted in the mistrust and fear of healthcare providers that continues today.[xviii, xix, xx, xxi, xxii]
    - Removed from families at birth with the family told their newborn/infant had died.
    - Removed from loving, supportive families with the families advised their child would be better off living in an institution.
    - Sterilized without consent.
    - Invasive medical procedures without consent.
    - Sexual and physical abuse.
    - Emotional neglect and psychological abuse.
    - Behavioural practices of seclusion.
    - Physical, mechanical and pharmacological restraints.

Trauma Impact

PWIDD are disproportionately impacted by traumatic experiences and trauma sequalae. Upwards of 70% of PWIDD experienced at least one traumatic event during their lifetime, with multiple experiences most common[xxiii]. Intentional efforts are needed for providers to more fully integrate trauma-informed care as part of each care encounter.[xxiv]

- Trauma triggers specific to healthcare:[xxv, xxvi, xxvii]
    - With any institutional-like exposure (sight, sounds, scents, building appearance).
    - Healthcare worker uniforms.
    - Undressing for medical examinations.
    - Restraining for medical procedures or behaviours.
    - Changes in routine during hospitalization.

The link between trauma and physical health is often overlooked in the lives of PWIDD. Many PWIDD who suffered institutional abuse are the individuals entering the healthcare stream now with life-limiting illness needs. It is imperative to consider trauma history context when providing healthcare for this population.[xxviii]

Healthcare Disparities Among Adults Living With IDD

- Access inequities; siloed and fractured care coordination
- Primary Care barriers and deficiencies
- Avoidable Emergency Department transfers
- Late identification; late referrals
- Morbidity/mortality patterns unrecognized (premature death)

Healthcare disparities result in high rates of Emergency Department (ED) use. Fifty percent of PWIDD visit the ED in a 2-year period and are 3-4 times more likely to be frequent visitors. A high portion of ED visits are considered potentially avoidable[xxix], many being Ambulatory Care Sensitive Conditions. This applies to most adults with IDD between 19–65 years; where increased frequency of admissions increase, on average, at age 40 with an average hospital length of stay of two weeks. PWIDD have poor hospital experiences and are at higher risk of poor outcomes. [vii, xxx, xxxi, xxxii, xxxiii, xxxiv]

Improving hospital care and post discharge, outpatient follow-up and community linkages may reduce 30-day returns to the ED among adults with IDD. Hospital discharge planning neglects to include the *DS* team. An unprepared *DS* team in part plays a role in 30-day repeat ED visits.

Existing data and research challenges, in part, have created barriers in demonstrating the needs of PWIDD to inform strategic direction, funding, and resource allocation.[vii, xxxv]

Healthcare disparities negatively impact timely palliative care. Timely responsive care is challenged by late identification of palliative care needs. This translates into over dependence on acute care and acute care PCUs (not dying in their preferred location). Late referrals to community-based palliative care teams are the result, in part, because earlier identification is challenged by tools that do not translate to

IDD thereby missing warning signs. Missed early warning signs lead to perceptions that PWIDD do not meet community palliative care programs intake criteria.

MEDICAL COMPLEXITY

Adults with IDD are a vulnerable population with complex health needs. The *Atlas on the Primary Care of Adults with Developmental Disabilities in Ontario*[ix] reported that adults with IDD are more likely than other adults to live in lower income neighbourhoods and have higher rates of chronic illness.

PWIDD's medical complexity has high rates of healthcare use and re-use, including emergency and inpatient hospital services, often due to physical and mental health dual diagnoses. PWIDD struggle to access preventive care and chronic disease management.

Compared to adults without developmental disabilities, adults with developmental disabilities consistently fared worse across five health outcomes:[xxxvi]

- 30-day repeat Emergency Department visits
- 30-day repeat hospitalizations
- Alternate level of care
- Long-term care
- Premature mortality

PREMATURE MORTALITY

Statistics Canada defines premature mortality as death before age 75 and avoidable mortality is defined as, "untimely deaths that should not occur in the presence of timely and effective healthcare, including prevention."[xxxvii]

A premature mortality pattern is observed for PWIDD of all age groups and both sexes regardless of economic status. Other broader determinants of health relate to the environment, provision of care, and access to healthcare services are major contributors to premature death.

Shorter life expectancy of PWIDD, for example greater morbidity and premature mortality, is in part due to substantial health inequalities, leading to poorer outcomes. IDD conditions often are themselves life-limiting.

PWIDD have four times the premature death rate to that of the general population based on the current evidence which is a known underestimate. Avoidable deaths are estimated at close to 50%; deaths that could be reduced with earlier access to good quality healthcare.

Cancer is emerging as a leading cause of death in PWIDD, with approximately 1.5 times more than the general population. Overall, 19% had a type of cancer that was a preventable cause of death. This mortality disparity may indicate adverse effects from inequalities in cancer screening resulting in late-stage diagnosis-limiting treatment choices.[xxxviii, xxxix, xl, xli, xlii, xliii]

Causes of Death[xliv, xlv]

- Cardio/Pulmonary
- Cancer
    - High incidence of gastric, bladder, colorectal, unknown primary malignancies
    - Higher risk of leukemia (Down syndrome)
- Sudden unexpected death in epilepsy (SUDEP)
- Congenital and chromosomal nervous system disorders
- Compounded by distinct frailty, higher rates of dementia, higher incidence of Alzheimer's Disease often with more rapid progression
    - In Down syndrome, Alzheimer's main or contributing cause of death[xlvi]

Median Age at Death by IDD Severity[xlvii]

- Mild: 68 years [IQ Range 58–77]
- Moderate: 64 years [IQ Range 52–75]
- Severe: 59 years [IQ Range 31–72]
- Profound and multiple: 46 years [IQ Range 41–68]

ENABLING THE WAY FORWARD
ADVANCING HIGH QUALITY PALLIATIVE CARE FOR PWIDD

International recommendations addressing healthcare disparities for PWIDD share commonalities with a palliative approach to care:

(i) Promote earlier identification
(ii) Address access inequities
(iii) Inclusion and self-determination of PWIDD
(iv) Prevent and manage the occurrence and impact of health conditions (proactive approach)
(v) Empower caregivers and family members in meeting care needs (education; meaning making; self and family advocacy

RECOMMENDATIONS

Acknowledging the above from a palliative approach to care, earlier identification, to be responsive to current and future needs, changing health status, advancing provider confidence across all care settings (healthcare; *Developmental Services*) in IDD specific palliative care requires commitment to:

1. **Strategies to develop provider confident competency in IDD palliative care**
2. **Supplement existing palliative care guidelines with IDD specificity and tools**
3. **Establish a Collaborative Team model with *Developmental Services* as the *Core Team* included to support care and decision making; communication with healthcare and palliative specialists; included in hospital-to-home discharge planning**
4. **Ensure IDD culturally appropriate, safe and sensitive palliative and end-of-life care**

1. Strategies to develop provider confidence and competency in IDD Palliative Care

- **Enabler:** Leverage *Developmental Services* and *Developmental Services Direct Support Professionals (DSPs)* to train healthcare providers in response to:
    - Barrier: Healthcare provider reports of insecurities when caring for PWIDD citing lack of confidence, being generally uncomfortable, a lack of experience or ignorance.
    - Barrier: Lack of confidence reservations manifest in reasons given for the omission of examinations or treatments for patients with multiple disabilities, in which judgments about PWIDD value, personhood, and quality of life become apparent, independent of the PWIDD informing their care and the PWIDD's will to live.
- **Enabler:** Leverage *Palliative Care specialists* to train *DS* and *DSPs* in response to:
    - Barrier: Reported lack of knowledge and experience in palliative care and at end-of-life due to lack of experience with the supported person often being sent to hospital at end-of-life (in part due to late ID, symptom crisis) or long-term care who are not better equipped in caring for PWIDD); but their desire is to deliver care-in-place including end-of-life care, preferring PWIDD to remain in their homes where the care team knows them best.
- **Enabler:** Leverage *DS* providers already delivering palliative and end-of-life care to mentor *DS* providers in IDD palliative care that are novices/experiencing their first end-of-life care in the home/congregate living environment.
- **Enabler:** Leverage IDD specific *Palliative Care healthcare providers* to mentor and enable Palliative Care Champion Models cross sector towards sustainable "good practices."

2. Augment existing palliative care guidelines with IDD specific palliative care "good practices" and IDD specific palliative care tools

- **Enabler:** Palliative Approach to Care principles are universal. However, there is a need for IDD specifications.
    - Barrier: Existing palliative care tools often do not translate well for use with PWIDD resulting in inaccurate estimation (over and under) of survival time (prognostication) and result in barriers to accessing community-based specialist palliative care teams.
- **Enabler:** IDD specific tools for *Advance Care Planning (ACP)*; *Healthcare Consent* (HCC); *Supported Decision Making* used by *DS* in communication to ensure understanding and informed decision making.
    - Barrier: Diagnostic overshadowing and assumptions that PWIDD are unable to participate in self-directing care.
    - Barrier: The person and their *Circle of Support* are less likely to receive crucial elements of essential patient-provider communication and essential conversations (delivering bad news; *ACP*; *HCC*; treatment options).
- **Enabler:** Healthcare to trust and act on *Circle of Support* as communication partners with the person supported.
    - Barrier: Communication barriers between person supported and healthcare make diagnosis and recognition of symptoms more difficult.
    - Barrier: Healthcare provider lack of time to allow the supported person to process.

- Barrier: Healthcare provider lack of acknowledgement of *DSPs* as the communication/translation experts.

- **Enabler:** Understanding behaviour(s) as a form of communication.
  - Barrier: Often misunderstood by healthcare providers.
  - Barrier: Can be interpreted as non-compliance (non-adherence) or a consequence of the impairment (diagnostic overshadowing) rather than an indication of pain, distress, or health status decline.
  - Barrier: Can result in overuse of sedation and anti-psychotics without psychiatric diagnosis.
  - Barrier: Can lead to infantilizing of adult PWIDD with inappropriate use of tools developed for use in pediatrics.
  - Barrier: Can compromise hospital-to-home discharge without continuity of care provisions, care coordination, and the provision of inadequate information.

3. Develop a collaborative team which includes Developmental Services

- **Enabler:** Optimize integration, shared understanding, navigation, and common language between healthcare and *Developmental Services* and their systems.
  - Barrier: Healthcare and *DS* have their own sector-specific common language that leads to misunderstanding, suffering, and safety issues.
  - Barrier: Family, *DSP*, caregivers report that healthcare providers often do not take their perspective into account.
  - Barrier: The *DSP* is not included in communication and/or behaviour translation.
  - Barrier: Are not seen as part of the care team proper and often can be excluded in care team communications due to misapplied confidentiality and consent practices.
  - Barrier: If *DS* expert teams remain uninvolved, healthcare providers will continue to lack competency in the care of PWIDD regardless of health settings.
  - Barrier: Assumptions remain that *DS* sector provides direct care in the community and duplicates service if *Home and Community Care Support Services (HCCSS)* are involved.

4. IDD culturally appropriate, safe, and sensitive palliative and end-of-life care

- **Enabler:** The care team must deploy ethical strategies to identify, prevent, and mitigate the following barriers and incorporate a Dignity In Care Approach (Dr. Harvey Chochinov):
  - Barrier: Unconscious bias leading to assumptions about PWIDD's Quality of Life.
  - Barrier: Autonomy is not respected.
  - Barrier: Lack of formal *Supported Decision Making* in Ontario, both legally and ethically.
  - Barrier: Lack of clinical tools to facilitate *Supported Decision Making*.
  - Barrier: Lack of culturally responsive care.
  - Barrier: Not receiving appropriate diagnostic screening, investigations, and assessments.
  - Barrier: Person's admissions/treatments is contingent on continuous accompaniment by *Circle of Support*.
  - Barrier: Inappropriate placement on geriatric or psychiatric unit instead of appropriate medically focused units.
  - Barrier: Additional time and resource allotment required at healthcare encounters influencing the quality of care provided.

    - Barrier: Assumption that PWIDD lack capacity to participate in *Advance Care Planning*, *Goals of Care* discussions, care planning, and provide *Healthcare Consent*.
    - Barrier: Assumption of inability to understand their illness, treatment options, and the concept of dying & death.
- **Enabler:** The *Care Team* will apply a trauma informed approach to care.
    - Barrier: The misconception that PWIDD do not experience trauma despite being at greater risk.
    - Barrier: Lack of consideration of possible institutional history and potential trauma triggers.
    - Barrier: Lack of awareness of the extent of trauma that PWIDD have experienced.
    - Barrier: Lack of awareness of therapies available for trauma care.
    - Barrier: Lack of awareness of the impact of unrecognized losses and grief.

Appendix A: Comparison Table of Guiding Principles

Federal Palliative Care Framework	OPCN Health Services Delivery Framework	Intellectual & Developmental Disabilities Palliative Care Network Toolkit
Palliative care is person- and family-centred care. Death, dying, grief and bereavement are a part of life. Caregivers are both providers and recipients of care. Palliative care is integrated and holistic. Access to palliative care is equitable. Palliative care recognizes and values the diversity of Canada and its peoples. Palliative care services are valued, understood, and adequately resourced. Palliative care is high quality and evidence based. Palliative care improves quality of life. Palliative care is a shared responsibility.	Centre around the needs and values of the individual patient and their family and take into account their cultural sensitivities and linguistic needs. Respect and support the important roles of substitute decision makers (SDMs) and the family. Enable access to equitable, high-quality, culturally safe, linguistically appropriate, and coordinated care as close to home as possible for all of the population in need. Ensure that interdisciplinary palliative care team members have the necessary competencies (including cultural safety and humility) and are working to their full scope of practice. Include capacity building to ensure a sustainable system of care for the future.	Palliative care is person-centred care with focus on self-determination of the individual with IDD. Palliative Care incorporates not only care for the person with IDD, but also extends to their circle of support. Palliative care is integrated into developmental service care delivery (across care settings and between care providers). Access to palliative care is equitable, inclusive, and addresses healthcare access inequities for PWIDD. Palliative care services are valued, understood comprehensively, collaboratively, and adequately resourced for the PWIDD. Palliative care is high quality and evidence informed. Palliative care is a shared responsibility. Palliative Care for PWIDD is guided by Ethics of Care.

Resources:

Consensus Norms for Palliative Care of People with Intellectual Disabilities in Europe, European Association for Palliative Care (EAPC), Taskforce on People with Intellectual Disabilities, APRIL 2015;

Delivering High Quality End of Life Care for People who have a Learning Disability, Resources and tips for commissioners, service providers and health and social care staff, NHS England, Palliative Care for People with Learning Disabilities Network (PCPLD Network);

Decision-making about the best place of palliative care for people with intellectual disabilities: a guide for care staff and healthcare professionals providing palliative care for people with intellectual disabilities;

Living and dying with dignity: the best practice guide to end-of-life care for people with a learning disability;

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