

MODULE C: CARE PATHWAY and INTEGRATED CARE TEAM MODEL GUIDANCE

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CARE PATHWAY

This *Care Pathway* is for adults with intellectual and developmental disability (IDD) receiving care in community settings who would benefit from a palliative approach to care. It has been adapted from the *Palliative Care Health Services Delivery Framework (PC HSDF)*, Ontario Palliative Care Network (OPCN) (2019)ⁱ.

It is recommended to use the PC HSDF along with this IDD specific care pathway to standardize palliative care processes for people with intellectual and developmental disability (PWIDD), their family, and *Circle of Support*. The aim is more equitable access, improved care coordination, and care team composition that integrates *Developmental Services* providers, healthcare and *Palliative Specialists* as one team.

Ethics Pearl: Caring is a practice that requires continuous effort. Competency in caring involves recognizing the need to collaborate with others, understanding where the limitation of one's skills are, and knowing who to reach out to for added support.



KNOWLEDGE POINTS:

The PC HSDFⁱ recommends a model of care in Ontario that will ensure:

- ▶ *“Palliative care is provided by an interdisciplinary palliative care team so that the right care is provided by the right provider.”*
 - **For PWIDD the team always formally includes *Developmental Services Professionals* with medical healthcare providers as one team.**
- ▶ *“The patient and their family/caregivers are actively engaged as members of the palliative care team and make decisions about their care.”*
 - **For PWIDD this is through *Supported Decision-Making* and uses language and communication in the way the person understands best.**
- ▶ *“The patient and their family/caregivers have seamless access to palliative care and support 24/7.”*
 - **For PWIDD this requires more time allotment for therapeutic interactions.**
- ▶ *“To ensure services are integrated, every patient will have a designated care coordinator.”*
 - **For PWIDD this includes their most trusted support person to serve as their care coordinator. This may be family, the congregate living home staff, *Developmental Services Complex Care Coordinators* and/or *Community Network of Specialized Care (CNSC) Healthcare Facilitators*.**

Ethical Reminder:

Equitable access and dignified inclusion for PWIDD requires:

- Collaboration with their most trusted support person(s)
- Service delivery by a team with IDD expertise
- Recognizing and meeting the person's needs using individualized resources and supports (such as assistive devices)
- Care provided in the location they identify as home

- ▶ “High-quality, person-centred palliative care is provided to patients wherever they are.”
- **For PWIDD quality care, quality of life and home is defined by the person to uphold their dignity and personhood.**

ACTION: “GOOD” PRACTICE STANDARD

The *Care Pathway* (see Appendix A) follows a standardized process and is further supported by the IDD Palliative Care Approach Process and Decision-Making Guidance. (see Appendix B)

The *Care Pathway* identifies the interdisciplinary members of the *Core Team*, *Extended Team* and *Palliative Specialists* involved. (see Appendix C)

- ▶ Identification
- ▶ Intake & comprehensive holistic assessment
- ▶ Ongoing care navigation coordination
- ▶ Integrated care team
- ▶ Ongoing assessment/ reassessment of need(s)
- ▶ End-of-life care
- ▶ Loss/grief and bereavement

INTEGRATED CARE TEAM MODEL

An integrated care team for PWIDD (Appendix C) may be referred to as a *Circle of Support*, circle of care, interdisciplinary, or interprofessional care team. Regardless of the term, the intent is a team consisting of a mix of roles and skill levels engaged in the same goal, same process of communication, collaboration, and coordination.

In the palliative approach to care the Foundational Principlesⁱⁱ of an integrated care team are:

1. Effective Team Function
2. Effective Communication
3. Being a Change Agent

The goal is the most person-centred, effective, and efficient care along the illness journey. As the illness journey progresses from chronic, advanced to end-stage illness, and through end-of-life the care team members evolve to meet the needs of the person, family, and *Circle of Support* (see Appendix D). To avoid gaps in care as illness progresses, the care team must seamlessly integrate the *Core Team* with *Extended Team* and *Palliative Care Specialists*.

An integrated care teamⁱⁱⁱ for PWIDD has as its foundation professionals who are familiar with adults with IDD. This is the *Developmental Services* providers who are joined by healthcare and palliative specialists. This integrated care team must function as one team for continuous, comprehensive, person-centred care.

INTEGRATED CARE TEAM

Well equipped care teams blend the strengths of Developmental Service Professionals with healthcare and Palliative Care providers as one team.



Ethics Pearl: Competency (specialized knowledge) in IDD is critical when creating our circle of support and integrated care team. This ensures that competent care is provided.

- ▶ Responsive care depends on close integration of *Developmental Services Professionals* with healthcare members of the *Core Team*, *Extended Team*, and *Palliative Specialists* **as one team**.
- ▶ There should be no impediment to information sharing that could negatively impact continuity of care delivery across the collaborative integrated care team.
- ▶ PWIDD provide advice to healthcare providers about how to improve their healthcare and the importance of an integrated team approach. See video [Better Practice, Better Health: Listening and learning from patients and families](#), Health Care Access Research and Developmental Disabilities (HCARDD)^{iv}.

ACTION: “GOOD” PRACTICE STANDARD

- ▶ Ensure PWIDD are surrounded by the people who know them best and want to be present. The person's *Circle of Support* may include friends, family, fellow residents, close neighbours, community members, *Direct Care Professionals (DCPs)* and others who know the person, their life story, and who the person trusts.
- ▶ To increase provider competency and confidence in IDD palliative care requires close integration of the *Core Team* of *Developmental Service (DS) Providers*, *Direct Care Professionals (DCPs)*, and *Primary Care*; Extended Services from DS and healthcare; and *Palliative Care Providers* both primary and specialist.
- ▶ Collaborative care model, integrating developmental services and healthcare sector strengths to positively impact a quality palliative approach to care.
- ▶ Shared cross sector capacity building, understanding and use of common language.
- ▶ Providers need to be equipped with IDD specific tools, given most palliative care standard tools do not transfer well for use for PWIDD.
- ▶ Health care providers must directly integrate the DS provider and *DSW* in care, including hospital to home discharge planning. Many PWIDD depend on their *DSW* as their communication partner/translators to enable the person to participate in care decision-making, to the extent of the person's wishes, and is capable of— particularly when there is no family involved.
- ▶ Having the *DSW* present and respected by the healthcare team during ER transfers and during hospital admission can decrease the stress and medicalized trauma triggers for the person.
- ▶ More time is required for therapeutic interactions. Appointments and in-home visits should be scheduled to ensure enough time is allotted.
- ▶ Use [Supported Decision-Making](#)^v to engage the person in their treatment process and continuing care.

RESOURCE LINKS and TOOLS

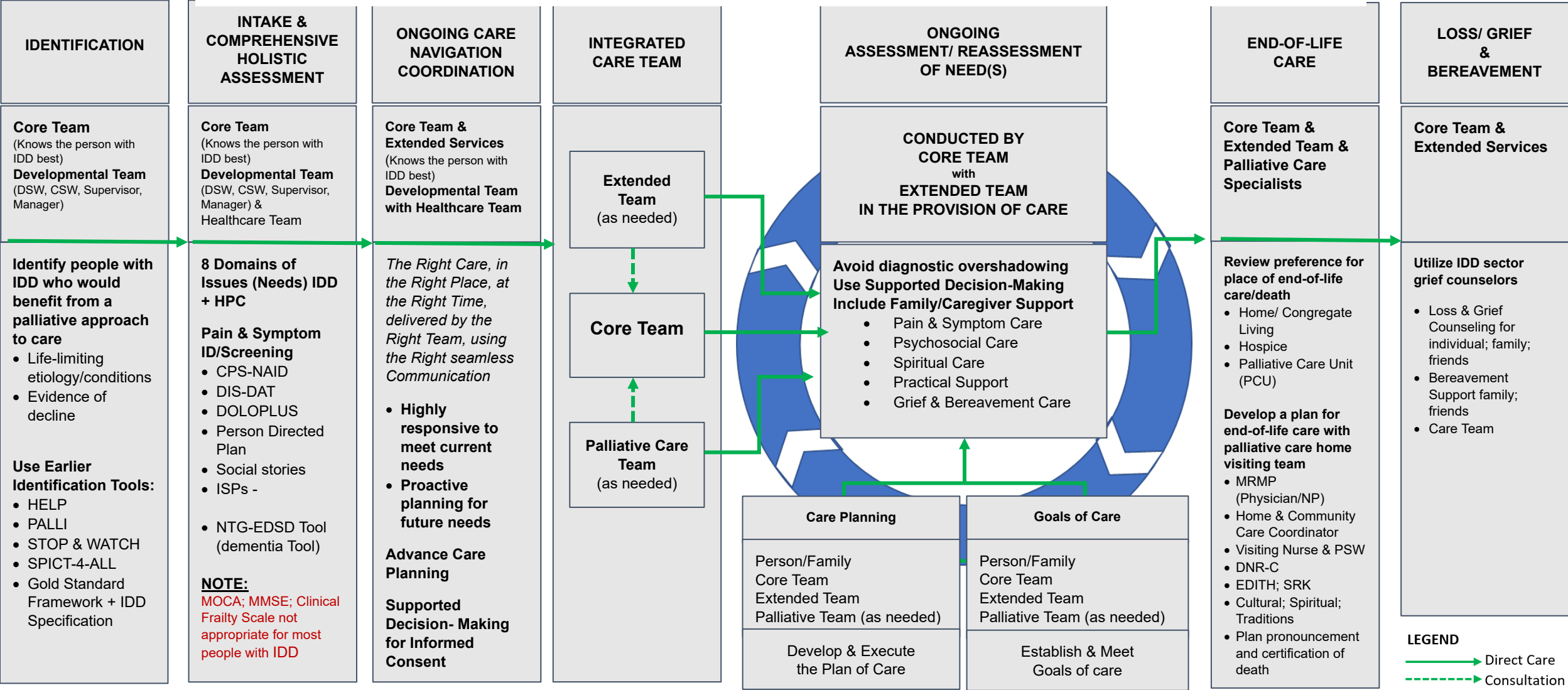
- ▶ [Consensus Norms for Palliative Care of People with Intellectual Disabilities, European Association for Palliative Care \(EAPC\) Taskforce on People with Intellectual Disabilities \(2015\)](#)
- ▶ [Palliative Care for People with Learning Disabilities Network and Resources \(PCPLD\)](#)
- ▶ [Developmental Disabilities Primary Care Program Home Page, Surrey Place](#)
- ▶ [Palliative Care Health Services Delivery Framework Models of Care, Ontario Health](#)
- ▶ [A Model to Guide Hospice Palliative Care: Based on National Principles and Norms of Practice, CHPCA, 2013](#)
- ▶ [Palliative Care Quality Standard, Ontario Health](#)
- ▶ [The Ontario Palliative Care Competency Framework, Ontario Health](#)
- ▶ <https://www.ontariohealth.ca/clinical/palliative/competency-framework>

Sharing information and Reporting to Healthcare providers:

- ▶ [My Hospital Form](#)
- ▶ [About My Health Form](#)

- ▶ **APPENDIX A: Patient Care Pathway Adapted for IDD**
- ▶ **APPENDIX B: IDD – Palliative Care Approach Process & Decision-Making**
- ▶ **APPENDIX C: Interdisciplinary Palliative Care Team Model for Adults with IDD in the Community**
- ▶ **APPENDIX D: Integrated Care Team Composition by Stage of Illness**
- ▶ **APPENDIX E: Palliative Care 3-Step Framework – Cue Sheet for Improved Integration of Developmental Services with Healthcare Providers**

APPENDIX A: PALLIATIVE CARE PATHWAY ADAPTED FOR IDD



Pathway assumes linear flow of care which may not be reflective of the real-life care trajectory

For people with IDD, the developmental services direct support team will be part of the interdisciplinary Palliative Care Team throughout the journey

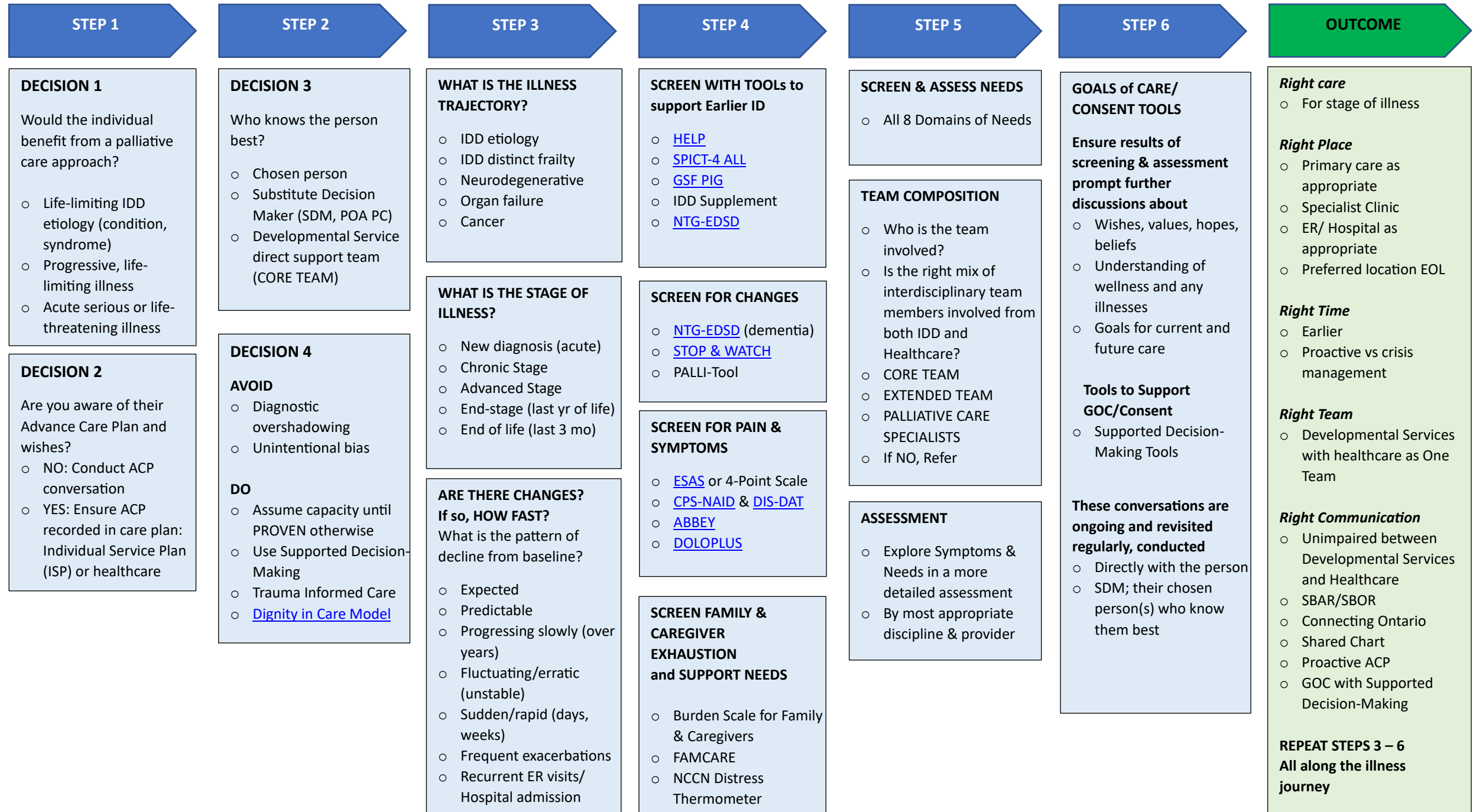
Acronyms
IDD – Intellectual and Developmental Disability
DS – Developmental Services
DSW – Direct Support Worker
HCCSS – Home and Community Care Support Services
ID – Identification
LTC – Long Term Care
MRMP – Most Responsible Medical Provider (Physician or NP)
SDM – Substitute Decision Maker

Palliative Care Health Services Delivery Framework: Patient Pathway Adapted for IDD

This diagram provides a summary of the Health Services Delivery Framework that depicts the key interactions between the person with IDD and their family/caregiver, the responsible provider/team members, and key decision points or responsibilities. The journey starts with earlier identification, followed by intake, assessment and referral to a Care Coordinator who connects the person with IDD and their family/caregiver with palliative care services. The diagram illustrates how care is provided by a collaborative interdisciplinary cross sector palliative care team consisting of developmental services providers with healthcare providers in three layers, the Core Team, Extended Services and Palliative Care Specialists. The pathway depicts care throughout the illness trajectory and features ongoing assessment of needs, supported decision-making, conversations about goals of care, regular updates to the care plan, care at the end of life, grief and bereavement care and supports for family/caregivers and the developmental services direct care team due to developmental services unique long-term therapeutic relationship and focused attachment.

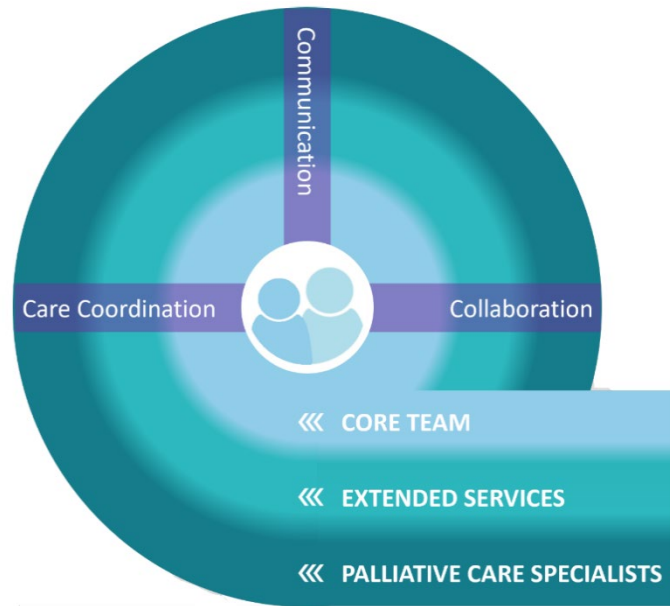
APPENDIX B

INTELLECTUAL and DEVELOPMENTAL DISABILITY – PALLIATIVE CARE APPROACH PROCESS & DECISION-MAKING



APPENDIX C

INTERDISCIPLINARY PALLIATIVE CARE TEAM MODEL FOR ADULTS WITH IDD IN THE COMMUNITY



CORE TEAM:

Healthcare

MRMP (MD/NP), Care Coordinator, Nurse (as needed), Patient/SDM, Family/Caregiver, Elder/Healer/Knowledge Carrier (First Nations, Inuit, Metis, and urban Indigenous

Developmental Services

Person with IDD, Family, SDM/Chosen person to assist with decision making, Direct Support Worker/Professional

EXTENDED SERVICES:

Healthcare

Community Services, Personal support, Pharmacist, Hospice, Volunteers, Indigenous Providers, Medical Specialists, Spiritual Care, Social Work, Rehabilitation Therapists, Dietician

Developmental Services

Behavioral Therapist; Psychiatrist; Social Worker, Speech Therapist, Health Service specialist in care of people with IDD e.g. IDD Nurse, Healthcare Facilitator, Complex Care Coordinator; IDD Specialist Clinics, Ethicists

PALLIATIVE SPECIALISTS:

Healthcare

Palliative MD/NP/RN, IDD Specialist MD/NP/RN, Palliative Care Consultants/PPSMC

Developmental Services

Psychosocial care provider/ Grief Counselor

Interdisciplinary Palliative Care Team Model for Adults with IDD in the Community

This figure contains the individual and family/caregiver icon surrounded by three concentric circles, demonstrating person-centered care. The innermost circle is the interdisciplinary Core Team of professional care providers which include the developmental services direct support team with the most responsible physician or nurse practitioner, and care coordinators. For First Nations, Inuit, Metis, and urban Indigenous communities, the Core Team also includes Elders, Knowledge Carriers and Healers. The middle circle is the Extended Services that includes community service providers, personal support workers, nurses, pharmacists, hospice services, volunteers, Indigenous providers, disease specialists, spiritual care providers, social workers, rehabilitation therapists, and dietitians. The outermost circle is Palliative Specialists that include palliative care physicians, nurse practitioners, nurses and psychosocial care providers with expertise in palliative care. Lastly, there is a purple bar across the circles labelled 'Coordination'. This bar represents coordination as an essential element of the model connecting providers and the person with IDD, their family, and circle of support (caregivers)

Adapted from Ontario Palliative Care Network (2019, April). *Palliative Care Health Services Delivery Framework, Recommendations for a Model of Care to Improve Palliative Care in Ontario, Focus Area 1: Adults Receiving Care in Community Settings*. pg 23.

APPENDIX D

INTEGRATED PALLIATIVE CARE TEAM COMPOSITION <i>Team evolves as needs change, illness progresses, and in response to acute events/exacerbations/emergencies that occur</i>				
TEAM MEMBERS	CHRONIC STAGE	ADVANCED STAGE	END-STAGE	END OF LIFE STAGE
CARE SETTING	Home/ SIL/ Congregate living	Home/ SIL/ Congregate living Long-term Care ER/ Hospital for acute event/exacerbation	Home/ SIL/ Congregate living Long-term Care ER/ Hospital for acute event/exacerbation	Home/ SIL/ Congregate living Long-term Care 24/7 in residence hospice Palliative Care Unit (PCU)
DEVELOPMENTAL SERVICE PROVIDER	CORE TEAM MEMBERS Person with IDD, Family, SDM/Chosen trusted person assisting with decision making - Direct Support Care Team (DSP, DSW, CSW) - Supported Living Services Supervisor/Manager EXTENDED TEAM MEMBERS - Special programs (e.g., respite, day programs) - Service Coordination - Therapists (Behavioral, Occupational, Physical) - Social Worker - Psychosocial, Grief Counsellor	CORE TEAM MEMBERS Person with IDD, Family, SDM/Chosen trusted person assisting with decision making - Direct Support Care Team (DSP, DSW, CSW) - Supported Living Services Supervisor and Manager EXTENDED TEAM MEMBERS - Special Services (e.g., Community Networks of Specialized Care, Complex Care Coordinators) - Therapists (Behavioral, Occupational) - Psychiatrists; Psychologists, Social Workers - Speech-Language Pathologists - Service Coordination (Family Support Workers, SWs) - Special programs (e.g., respite, day programs) - Psychosocial, Grief Counsellor - Bioethicist as appropriate	CORE TEAM MEMBERS Person with IDD, Family, SDM/Chosen trusted person assisting with decision making - Direct Support Care Team (DSP, DSW, CSW) - Supervisor; Manager EXTENDED TEAM MEMBERS - DS Special Services (e.g., Community Networks of Specialized Care; Complex Care Coordinators) - Social Workers, Psychosocial, - Counsellor Grief and Bereavement care - Bioethicists as appropriate	CORE TEAM MEMBERS Person with IDD, Family, SDM/Chosen trusted person assisting with decision making - Direct Support Care Team (DSP, DSW, CSW) - Supervisor; Manager EXTENDED TEAM MEMBERS - DS Special Services (e.g., Community Networks of Specialized Care; Complex Care Coordinators) - Social Workers, Psychosocial, - Counsellor Grief and Bereavement care - Bioethicists as appropriate
HEALTHCARE or PALLIATIVE CARE PROVIDER	CORE TEAM - MRMP (Primary Care MD; NP) - Specialized IDD Health Care Providers - Pharmacists EXTENDED TEAM MEMBERS - Care Coordinators; Case Managers - Specialists Care (neurology, psychiatry, cardiology, renal, geriatrics, acute care/ER, etc.) - Nurses; PSWs - Allied Health professionals, (e.g., dietitians, physical, occupational, recreational therapists)	CORE TEAM - MRMP (Primary Care MD; NP) - Specialized IDD Health Care Providers - Pharmacists EXTENDED TEAM MEMBERS - Care Coordinators; Case Managers - Specialists Care (neurology, psychiatry, cardiology, respiratory, renal, geriatrics, acute care/ER, etc.) - Nurses; PSWs - Allied Health Professionals, (e.g., dietitians, physical, occupational, recreational therapists)	CORE TEAM - MRMP (Primary Care MD; NP) - Specialized IDD Health Care Providers - Pharmacists EXTENDED TEAM MEMBERS - Care Coordinators; Case Managers - Specialists Care (neurology, psychiatry, cardiology, respiratory, renal, geriatrics, acute care/ER, etc.) - Nurses; PSWs and Allied Health Professionals, (e.g., dietitians, physical, occupational, recreational therapists) PALLIATIVE SPECIALISTS - Palliative Physician/NP (tertiary, home visiting) - Palliative Nurses (RN, RPN), PSWs - PSPMCs (Pain & Symptom Management Consultants) - Hospice (Intake, Inpatient, Outreach, Community programs, volunteers) - Grief & Bereavement Care; Spiritual Care	CORE TEAM - MRMP (Primary Care MD; NP) - Pharmacist EXTENDED TEAM MEMBERS - HCCSS Care Coordinator - Respiratory Therapist PALLIATIVE SPECIALISTS - Physician (home visiting, PCU) - Palliative Nurse Practitioners (HCCSS home-visiting) - Pharmacist/ HCCSS Pharmacy provider - End-of-life home-visiting nursing team - End-of-life home-visiting PSW support - Hospice (Inpatient or Community) - PSPMCs (Pain & Symptom Management Consultants) - Grief & Bereavement Care; Spiritual Care

PALLIATIVE CARE 3-STEP FRAMEWORK – CUE SHEET FOR IMPROVED INTEGRATION OF DEVELOPMENTAL SERVICES WITH HEALTHCARE PROVIDERS



KNOW

THINK



Know the IDD etiology/condition well. Know enough about the medical Diagnoses/Comorbidities.

- How is the combination of IDD etiology (cause) + medical conditions impacting the person and family's experience?
- What do you need to understand/who will you ask to be effective in your role?

What Issues/Needs could the person present with?

What could the person have risk(s) for?

- Not exhaustive – e.g., exacerbations; relapses; progressive decline changes; sudden erratic changes
- Recurrent infections? aspirations? ER transfers/hospitalizations? breakthrough seizures? Increased risk of cancer? Others?

Where are the decision-making points?

- Is Supported Decision-Making being used? Guide Health care providers to do so

What Practice Guideline (BPG) can you refer to and use?

IDENTIFY
&
SCREEN



Where are they on the Illness Trajectory & Stage of Illness? What does it mean?

- What Illness Trajectory? – Cancer; Organ Failure; Neuro-degenerative/Frailty
- What Stage of Disease? – new Diagnosis (Dx), chronic, advanced, end stage, end of life

What are the Issues/Needs active and potential future needs?

- What is person/ family/ Direct Care Support Workers (DSW) concern(s) & Priority?
- What is your concern(s) & Priority?

Is there a change from their normal baseline? If YES, how much? What Tool(s) will you select, use, or guide others screening?

What Tools will you select/advise using for Pain & Symptom(s) Identification & Screening for this person?

- Who needs to conduct a Targeted Assessment for pain/symptoms to validate; confirm; rule out?

Act, Guide and Support person/family/direct care support workers actions on identified concerns/issues

Use SBOR or SBAR reporting tool to communicate concerns to Health care providers

OBSERVE
ASSESS
CONNECT
DO



Zero in on the Priority Area(s) needing Assessment; Eventually assess for all issues across all 8 Domains

- Are you the one conducting the assessment, or does it require a different provider/scope of practice?

What Tools are recommended to be used to do a thorough assessment? Select & Use/ Guide others to use

What are your findings? How concerned are you? Why are they occurring? What do your findings mean?

What needs to be done?

- Prioritize accurately & Move to Action – get issues/needs optimally addressed/ controlled
- Eventually address all issues in a timely & responsive manner

Be Proactive – Earlier Identification is better than being forced into reactive/crisis management

- What needs to be in place now and for the future? What risks need to be prepared for?
- What essential conversations need to take place based on medically expected outcome/informed Goals of Care (GOC)s?

**WHO IS THE COLLABORATIVE TEAM THAT NEEDS TO BE IN PLACE (DS with Healthcare)?
INFORM & TEACH; CHECK UNDERSTANDING; EMPOWER SUPPORTED DECISION-MAKING; RETURN DIGNITY.**

REFERENCES

- ⁱ Ontario Palliative Care Network (2019, April). *Palliative Care Health Services Delivery Framework, Recommendations for a Model of Care to Improve Palliative Care in Ontario, Focus Area 1: Adults Receiving Care in Community Settings*. <https://www.ontariohealth.ca/content/dam/ontariohealth/documents/palliative-adult-care-community-setting.pdf>
- ⁱⁱ Canadian Hospice Palliative Care Association (2013). *A Model to Guide Hospice Palliative Care*. Ottawa, ON: Canadian Hospice. <https://www.chpca.ca/wp-content/uploads/2024/07/norms-of-practice-eng-web.pdf>
- ⁱⁱⁱ Surrey Place (2024). Interprofessional Health Care Teams. <https://ddprimarycare.surreyplace.ca/guidelines/general-health/inter-professional-health-care-teams/#:~:text=Engage%20in%20or%20support%20developing,therapists%2C%20physiotherapists%2C%20psychologists%2C%20behaviour>
- ^{iv} Health Care Access Research and Developmental Disabilities [H-CARDD] (2027, April 28). *Better Practice, Better Health: Listening and learning from patients and families* [Video]. YouTube. <https://www.youtube.com/watch?v=7gRmdbEe65c>
- ^v Supported Decision Making framework and resource <https://waindividualisedservices.org.au/supported-decision-making-resources/>