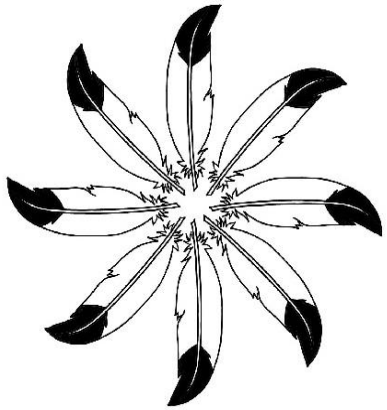
Improving End-of-Life Care in First Nations Communities:



Engaging Stakeholders in Journey Mapping: Creating and Implementing a Palliative Care Pathway for Clients living in Naotkamegwanning First Nation

CIHR IRSC
Canadian Institutes of Health Research | Instituts de recherche en santé du Canada

Lakehead UNIVERSITY | Centre for Education and Research on Aging & Health

Objectives:

- Review the journey mapping process to develop the care pathway
- Importance of engaging with internal and external partners
- How to identify barriers and capacities and generate ideas to improve the client journey
- Implementation of the journey map including developing and implementing a care pathway and creating new policies and recommendations

Background

- This initiative was part of a 5 year (2010-2015) CIHR funded research project “Improving End-of-Life Care in First Nations Communities” (EOLFN)
- The overall goal of this project was to ***improve end-of-life care*** in four First Nations communities by developing local palliative care programs and teams, and
- Create a ***workbook for developing palliative care*** programs in First Nations communities that will be shared nationally

First Nations Community Partners

www.mapsof world.com

Naotkamegwanning First Nation

- Naotkamegwanning is located in North Western Ontario in the heart of the Treaty #3 Territory
- The nearest urban center Kenora (approx. 15,000 people) is 96 km north of NFN
- The community has year-round road access and also has an ice road in winter
- There are 712 community members living in the community

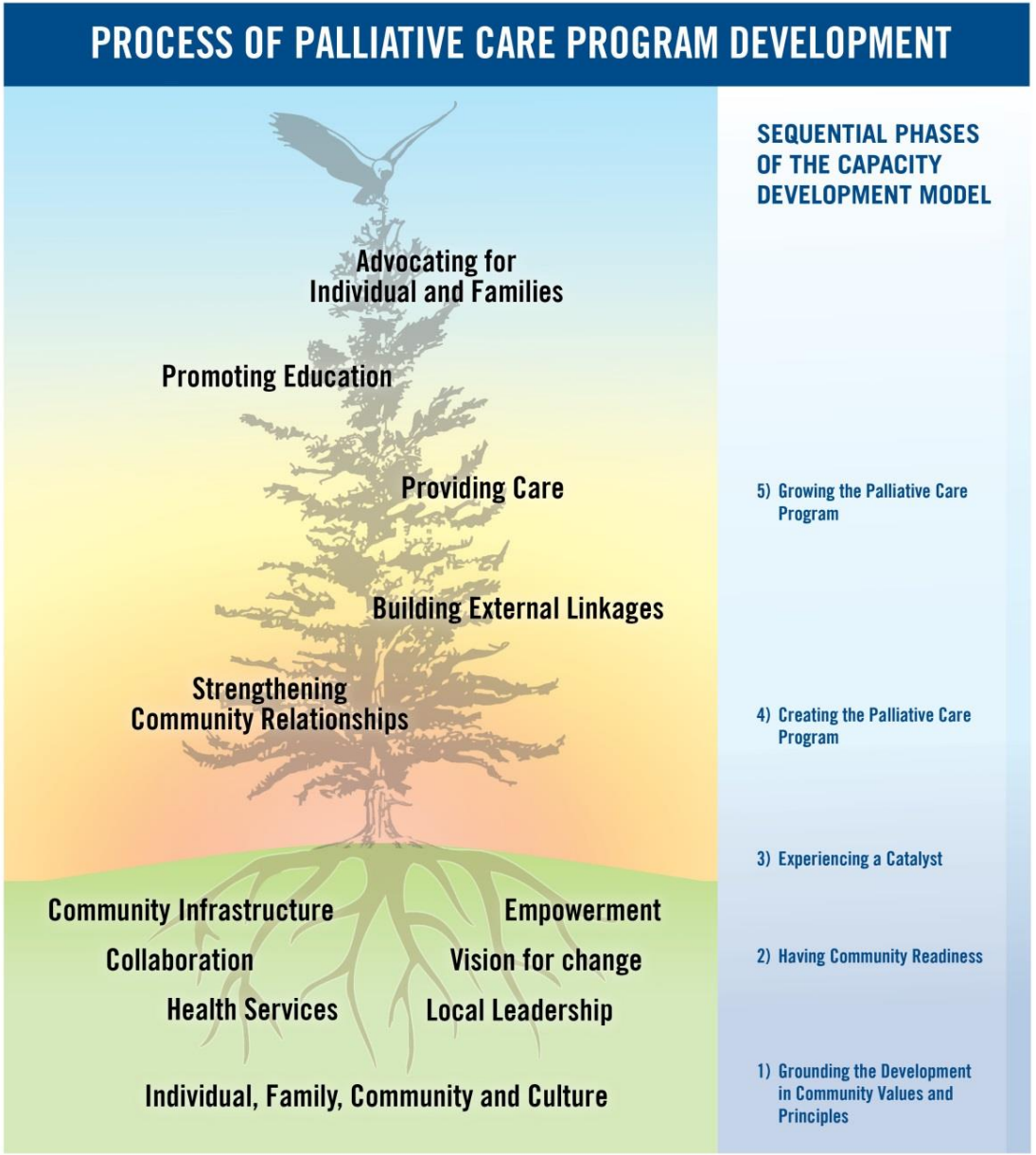
Cultural Identity

- NFN is one of the very few communities that have been able to keep their Anishinaabe cultural practices and beliefs strong and vibrant
- 48% of the population are able to speak Ojibway
- Many of the people of NFN continue a connection with the land and maintain a lifestyle that includes fishing, hunting & harvesting of wild rice
- The importance of passing on teachings, language and cultural practices are evident in their delivery of programs and services within the community
- Community cultural context strongly impacts the way death and dying is viewed and discussed in the community

Health System Barriers at EOL

- Communication and language barriers
- Lack of cultural safety and competency (hospital culture)
- Inadequate hospital discharge planning
- Health system lacks understanding of FNIHB & NIHB policies and procedures
- Lack of timely access to medication and equipment in FN community
- Lack of support for client choice to die at home
- Lack of palliative home care services in FN communities

ASSESSING THE COMMUNITY READINESS AND VISION FOR CHANGE



Palliative Care Journey Map

- The palliative care journey map is a process flowchart accompanied by a narrative that illustrates a typical client's progression through the health care system.
- The map encompasses medical and psychosocial supports and highlights care options in various settings such as home, hospital and long term care.
- It illustrates the "current state" interaction with services and providers and the desired "future state" of care.

Step 1

Focus is work in the community.

Educate and engage the community

Leadership Team

- A local health care provider needs to take the lead and determine if there is an interest in establishing a palliative care program in the community
- A leadership team then needs to be developed to identify the vision and take responsibility to lead the process
- These people are local community members from various health care programs, local service providers, Elders, members of leadership, and invested community members
- The team can develop a terms of reference if desired

Assessing Community Readiness

- Leadership team then meets several times as a group to complete the five EOLFN “Assessing Community Readiness” tables
- These tables focus on five areas:
  1. Assessment of local health infrastructure & palliative care services
  2. Where are palliative care services being provided?
  3. Assessing community strengths
  4. Assessing & prioritizing gaps in services and challenges to overcome
  5. Plan for action

Table 1: Assessment of local health infrastructure & palliative care services

Name of Agency/Provider	What services do they provide?	How can they be accessed?	Do they have a representative on the team?

Table 2: Where are palliative care services being provided?

Location of services	List of services that are provided here	Any gaps?
In the client's home	e.g. homemaking, nursing, spiritual care, volunteer visits	
In the community	e.g. support groups, education/information sessions	
In the hospital / clinic	e.g. interprofessional case conferencing, pain & symptom management	
In long-term care	e.g. pain & symptom management, volunteer visits, spiritual care	
Outside the community		

Table 3: Assessing community strengths

	Strengths
Community Characteristics	e.g. closeknittedness, level of volunteerism
Service/Care Provider Characteristics	e.g. existing relationships, knowledge, skills, experience
Type/Quality/Accessibility/ Delivery of Services	

Table 4: Assessing & prioritizing gaps in services and challenges to overcome

Think about the gaps in service and challenges that your community faces. Identify which gaps are the most important for your team to address (e.g. what gaps do we need to work on filling right away?). Next, identify which challenges will be most important for your team/community to overcome in order for you to “succeed”.

	1 Most Important	2	3	4	5 Least Important
Gaps in Service					
Challenges to Overcome					

Table 5: Plan for action

Think about your long-term vision and what you will need to do to see it realized. Make a list of all of the goals that you need to be working on in order to transform your vision into reality. To keep from being overwhelmed, start out by listing 2 or 3 short-term goals that are both specific and achievable.

Goal	Actions That Need to Be Taken to Achieve Goal	Timeline	Who is Responsible?

Step 2

Engaging Regional Partners and Establishing a Stakeholder Working Group

Educating and Engaging Regional Stakeholders

- After completing the five charts, the leadership team (LT) then engages with all the external health care providers (HCP) that currently provide service or have the potential to provide service for care of a client in their community

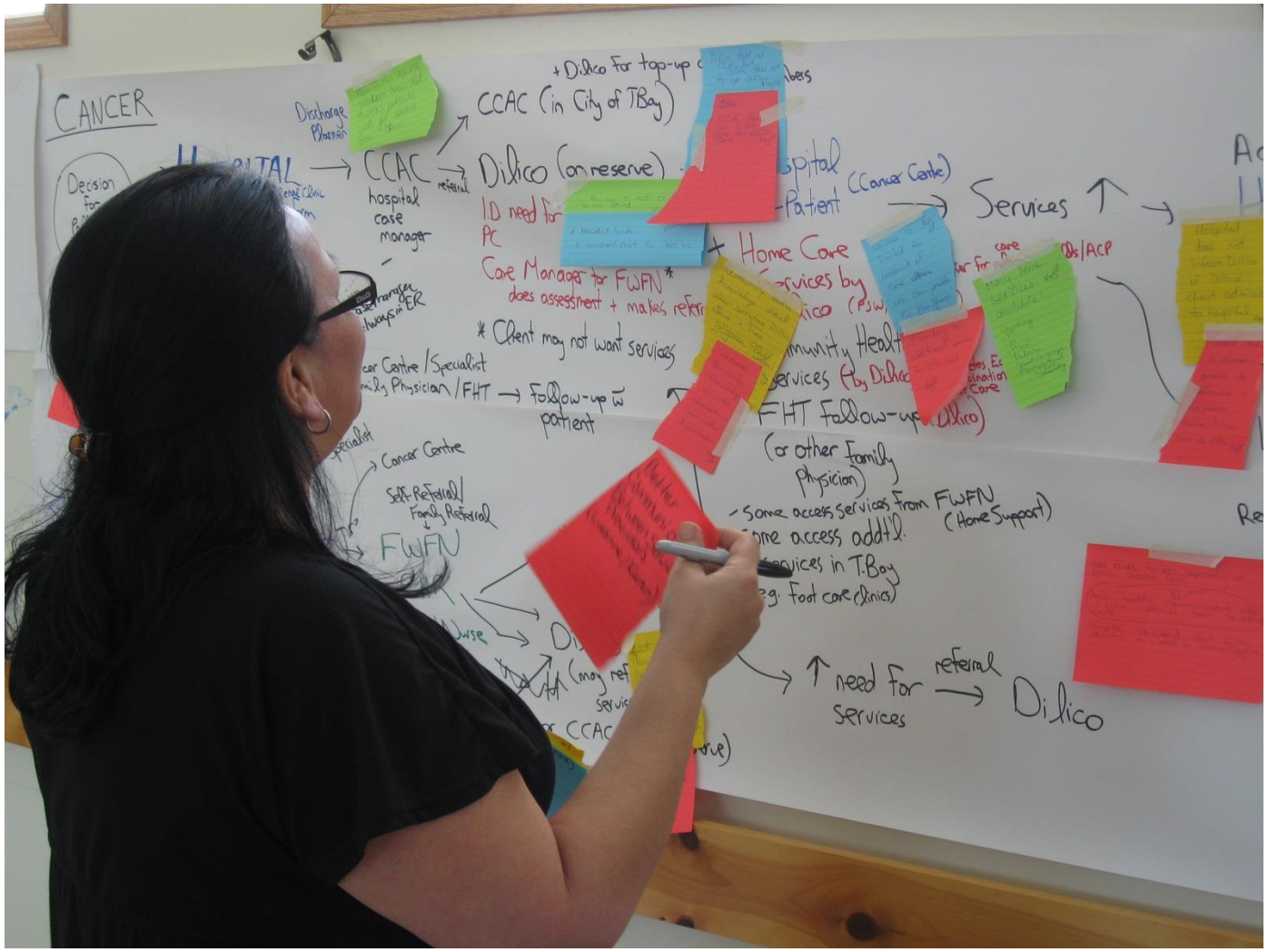
- The LT then invites all of the external HCP to attend a workshop with the intention of engaging with them to provide better quality care for their clients and understand each others roles

- Prior to the workshop, the leadership would plan the following: (1) Decide who will facilitate the workshop and who will record it, (2) Write out the nine steps on a large piece of paper to be displayed in the room, (3) Prepare packages for everyone; including an agenda and the five charts, and (4) ensure workshop supplies include four different colour sticky notes, markers, and roll of paper

- First the leadership team would discuss with the group their vision and intent
- Second, the facilitator would present the EOLFN “assessing community readiness charts” and engage the providers in validating and enhancing them
- Next, the facilitator would take the group through the series of steps to discuss what is happening today with a client who is seriously ill (Current State)
  - Each step, would be then be described in detail answering the “who, what, when, where, how and why”.


How/where are clients identified?
How/where is client referred?
Is there a comprehensive assessment?
Where/who?
Is there a case conference and development of care plan?
Where/who?
Who provides services?
How are services coordinated?
Does the client have the choice to die at home?
Who provides follow-up and bereavement support?
Case closure
Who / What / When / Where / How / Why?

- For each step, the facilitator would ask everyone to answer four questions, each on a specific coloured sticky note:
  - What is working well? (green sticky note)
  - Where do things go wrong? (yellow sticky note)
  - Where are the gaps and unmet needs? (red sticky note)
  - What are your solutions and ideas? (blue sticky note)
- Once they are done answering the four questions, they would place their different coloured sticky notes beside each step


CANCER
CCAC (in City of TBay)
CCAC
hospital case manager
Dilico (on reserve)
referral
Care Manager for FWFN*
does assessment + makes referr
* Client may not want services
Home Care
Services
Cancer Centre
Self-Referral/ Family Referral
FWFN
(or other family physician)
- some access services from FWFN (Home Support)
need for services
referral
Dilico

Documenting the Current State

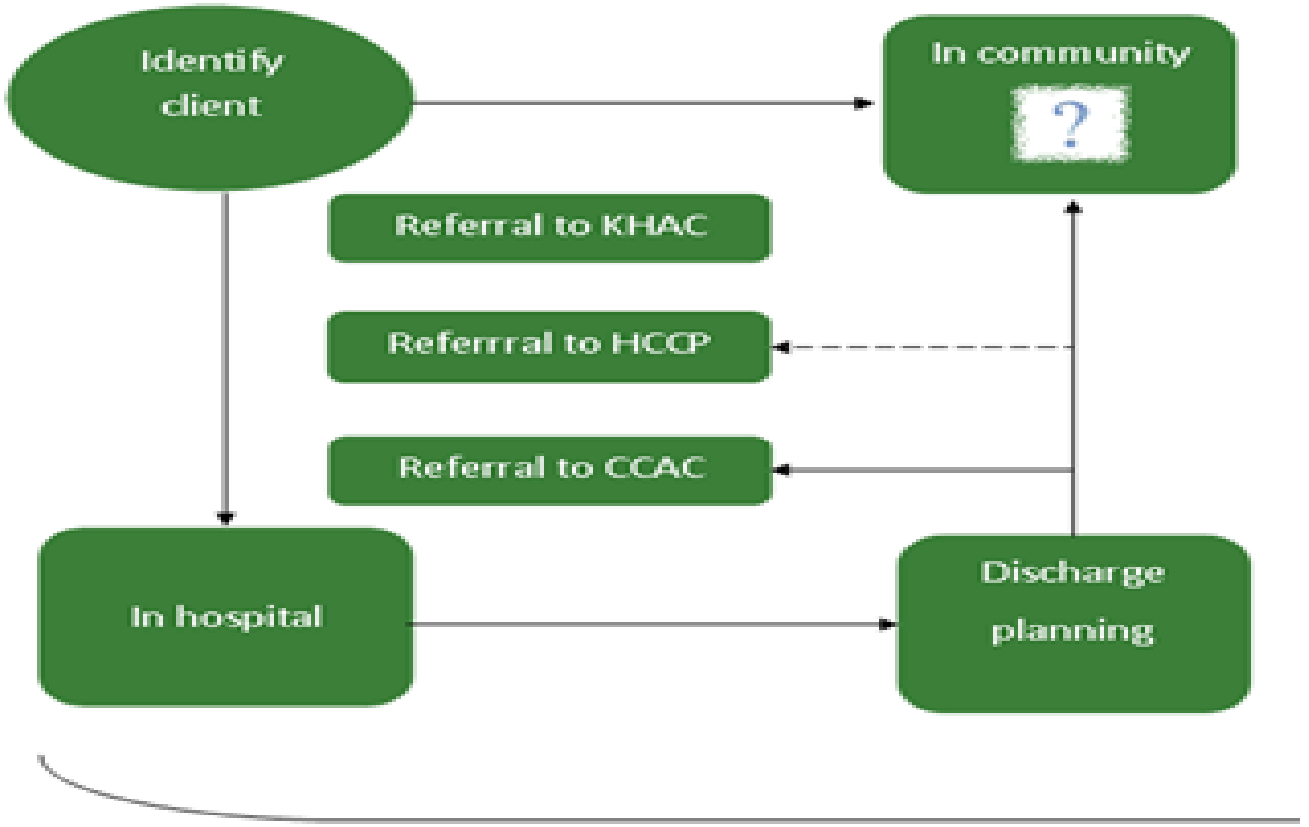
Steps	What is already in place	What is working well?	Where do things go wrong?	Gaps and unmet needs?	Solutions and ideas?
How and where client is identified	Points of entry Program criteria				
How/where is client referred	Community referral process				
Is there a comprehensive assessment? Where/who?					
Is there a case conference and development of care plan? Where/who?					
Who provides services?					

Steps	What is already in place	What is working well?	Where do things go wrong?	Gaps and unmet needs?	Solutions and ideas?
How are services Coordinated?					
Does the client have the choice to die at home?					
Who provides follow-up and bereavement support?					
Case closure					

Homework after the meeting

- The leadership team will create a report summarizing the steps and the four questions/responses and send it to everyone that was at the workshop
- The external health care providers need to discuss the report internally within their organizations
- The leadership team needs to draft out the future desired state from the community perspective

Example: Problems in the Current State

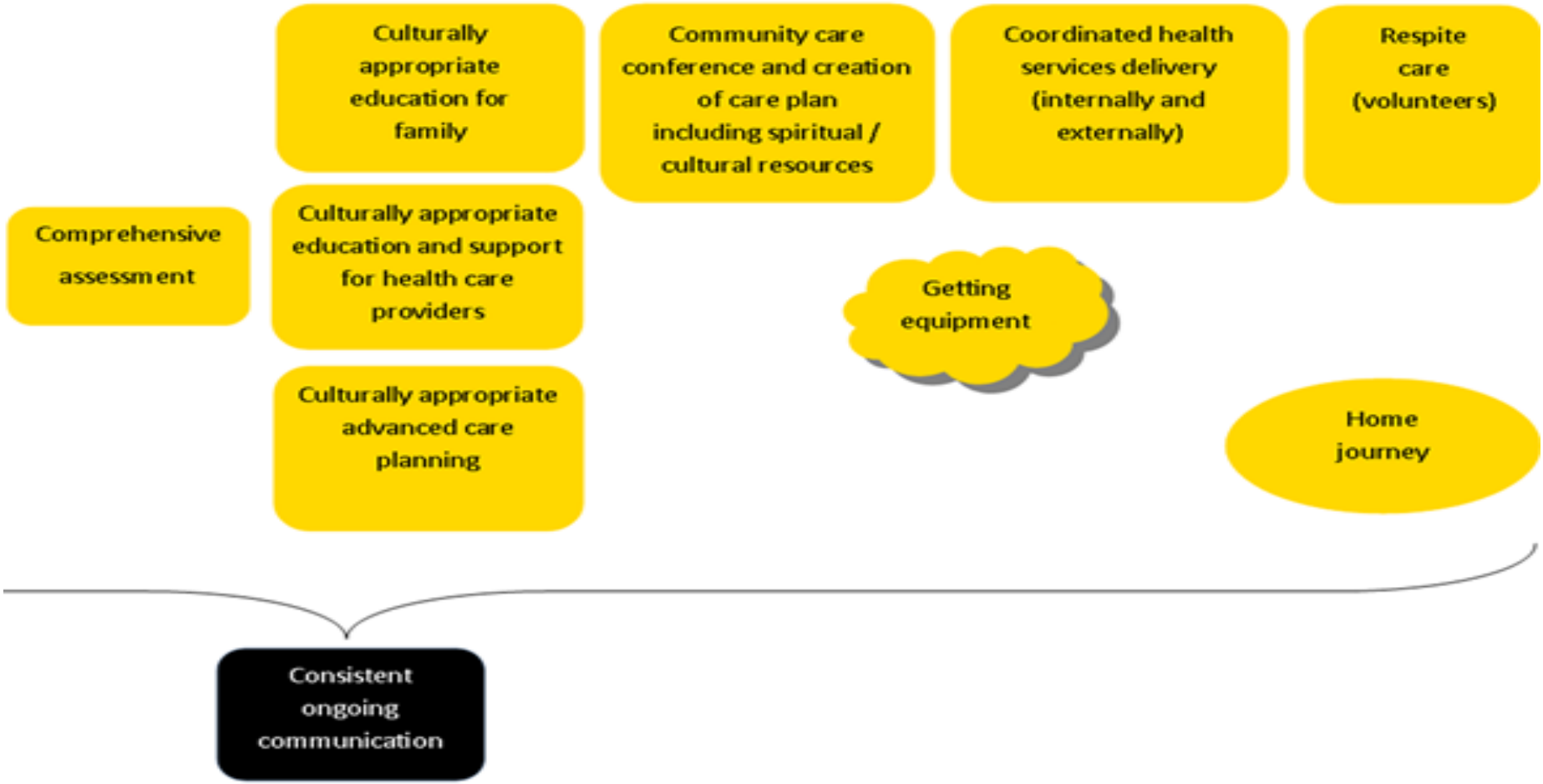


CCAC — Community Care Access Centre

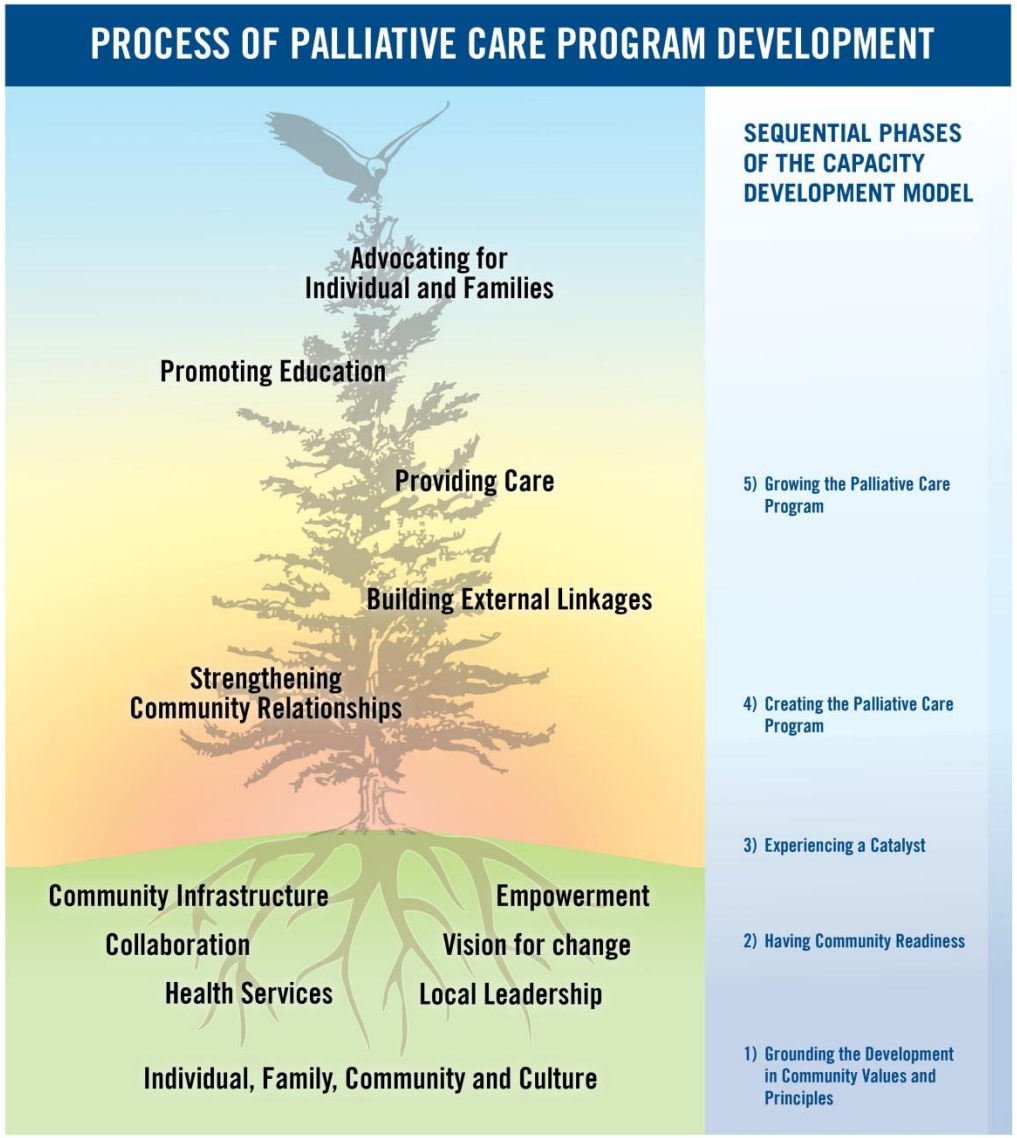
HCCP — Naotkamegwanning Home and Community Care Program

KHAC – Kenora Health Access Centre

Example: Desired Future State in the Community



CREATING AND IMPLEMENTING THE VISION



Future Desired Care Pathway

- After the individuals have had a chance to review the first workshop report internally, the leadership team would then schedule a second workshop in order to create the vision for the new care pathway using the care path template.

- Prior the workshop, the leadership would plan the following: (1) Decide who will facilitate the workshop and who will record it, (2) Write out and create a diagram of the desired future state on a large piece of paper to be displayed in the room, (3) Prepare packages for everyone; including an agenda and the a copy of the desired future state, and (4) ensure supplies include four different colour sticky notes, markers and a roll of paper

- Present the future desired state from community perspective (9 step care pathway) and then get the providers to discuss and see how these steps be implemented.
- Review the gaps and barriers and discuss how the ideas and solutions could be implemented.
- Develop an action plan for steps 1-5 and identify the external care providers and their roles.
- Outcome is a diagram of the future state and a draft workplan that identifies what each person/organization needs to do.

Steps 1-5 with external care partners

Steps 1-5	What is already in place	Key process and consent	What needs to be accomplished/ implemented	Decisions to be made	Stakeholders
Client is Identified	Points of entry Program criteria	Information sharing (what and to whom)			
Client is Referred	Community referral process	Information sharing (what and to whom)			
Comprehensive Assessment		Information sharing (what and to whom)			
Case Conference and Creation of a Care Plan		Information sharing (who is in the Circle of Care)			
Coordinated Health Care Deliver		Information sharing (what and to whom)			

Homework following the workshop

- The leadership team will create a report summarizing the action plan and send it to everyone that was at the workshop
- The external health care providers need to discuss the report internally within their organizations
- The leadership team needs to develop their action plan for steps 6-9 internally as a community

Steps 6-9 with internal care partners

Steps 1-5	What is already in place	Key process and consent	What needs to be accomplished/ implemented	Decisions to be made	Stakeholders
Planning for Passing	Points of entry Program criteria	Information sharing (what and to whom)			
Client has Passed	Community referral process	Information sharing (what and to whom)			
Follow-up and Bereavement Support		Information sharing (what and to whom)			
Case Closure		Information sharing (who is in the Circle of Care)			

Individual Meetings

- The leadership team will then set-up individual meetings either in person or on the telephone with each major stakeholder to discuss their role.
- The action plan will be used as a guide to facilitate this discussion and will also formalize the relationship
- Following this discussion, the action plan may need to be revised and agreed upon
- A representative from the leadership team is responsible for updating and revising the action plan

Formalizing the Program

- The leadership team in collaboration with the external partners develops the First Nations program guidelines which includes: eligibility criteria and referral process, mission and vision statement of the program, the care pathway, list of specific services and contact information.

Implementing the Care Pathway

- Client identification
- Case conferencing
- Client assessment tools and processes
- Education and support for family and health care providers
- Communication and coordination
- Respite care and volunteer program

Celebration of the New Process

- Once the care pathway has been developed and implemented, the leadership team should organize a celebration to highlight the strengthened external partnerships and to evaluate the plan for the new process

Plan for Follow-up and Evaluation

- Living document
- Revisit/revise the care pathway after providing care to two residents that have passed.
- Ongoing plan for evaluation and quality improvement

Lessons Learned

- The importance of developing strong partnerships with external care providers - developing the care path requires a real commitment of time and resources from these providers
- The importance of making certain that communication lines between all parties are open
- The importance of ensuring that the community feels that they maintain ownership of the process
- The importance of ensuring that the care path is culturally appropriate and inclusive of traditional practices and beliefs

Acknowledgements

SIX NATIONS COUNCIL

KAOTKAMEGWANNING FIRST NATION

Fort William First Nation

CIHR IRSC
Canadian Institutes of Health Research
Instituts de recherche en santé du Canada

Peguis First Nation

Dilico
Anishinabek Family Care

Lakehead UNIVERSITY
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