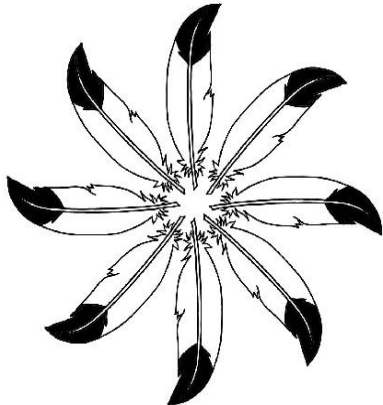


# Improving End-of-Life Care in First Nations Communities



## Conducting Participatory Action Research with First Nations Communities: Lessons Learned from a 5yr CIHR Study

*CHPCA, October 2015*

*Ottawa, Ontario*

# Overview of Research Project

- Funded for 5 years (2010-2015) by CIHR
- CERAH, Lakehead University was host organization
- 4 First Nations communities were partners in this project:
  - Six Nations of the Grand River Territory
  - Fort William First Nation
  - Naotkamegwanning First Nation
  - Peguis First Nation

# Goals of the Project

- 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 can be shared nationally

# Phases of the Research Project

- Researchers and local First Nation Community Facilitators worked in each community to conduct a community needs assessment through a local Project Advisory Committee
- Based on the data collected, specific strategies were identified by each First Nation community and have been implemented by the community over five years
- These strategies were evaluated for effectiveness in contributing to the overall change process in developing a local palliative care program
- The research-informed strategies will contributed to a “workbook” of guidelines for developing local community capacity to provide palliative/comfort care in First Nations communities

# Highlights of Results

- The majority of survey participants (87%) felt that, if services were available and adequate, community members would choose to die at home.
- 66% of survey respondents felt that talking about death and dying is acceptable in their community.
- When asked how they felt about EOL care planning, 68% of survey participants felt it should be done while still healthy, while 24% felt that you can't plan for end-of-life, planning happens when you need it.

# Benefits to dying at home

- Supports in community provided by family, community members, and informal volunteers
- Access to culturally safe and culturally relevant care, including access to traditional language
- Familiarity and comfort of home
- Transportation would not be an issue (including costs)

# Community Challenges to Dying at Home

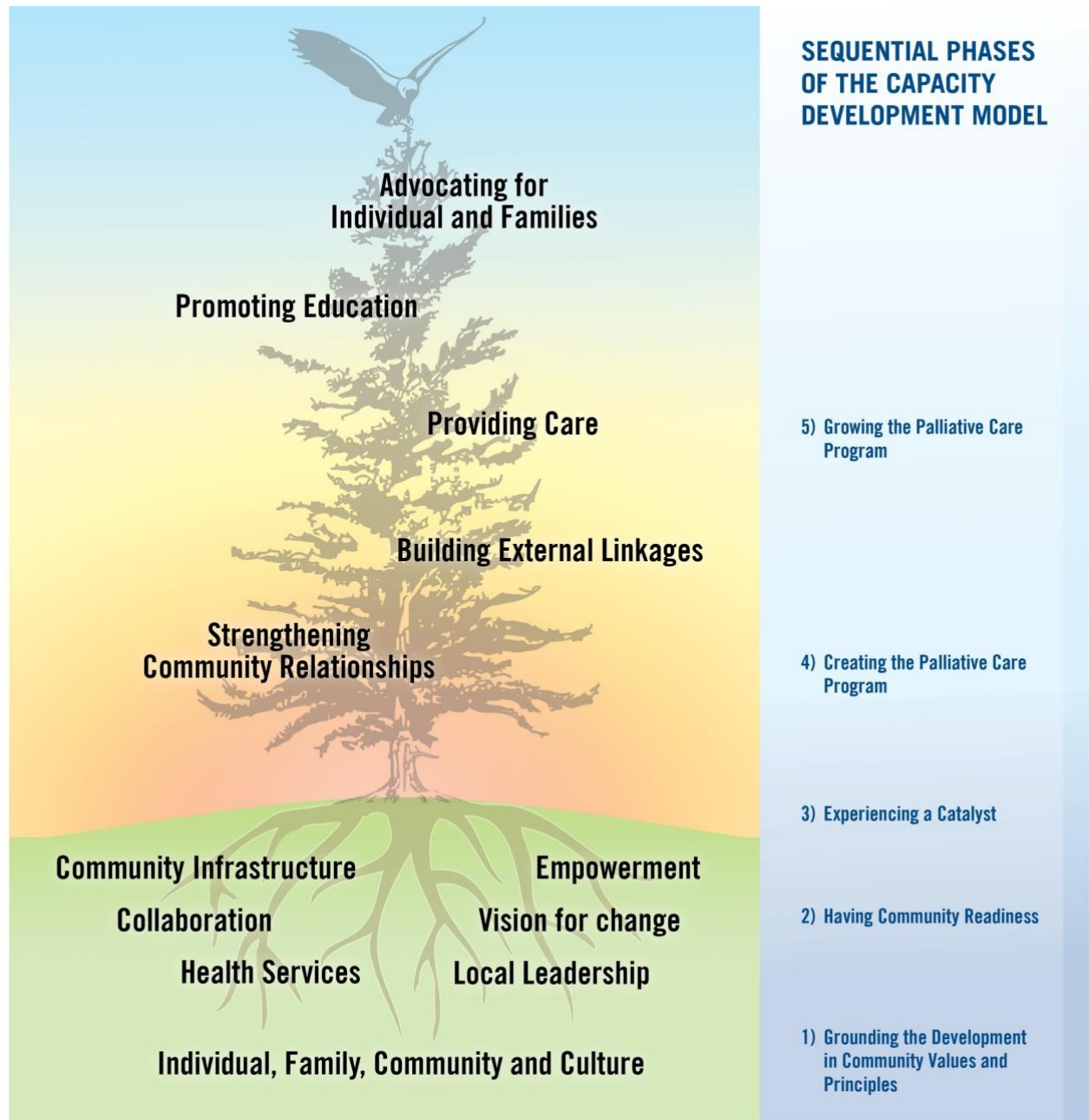
- Talking about death and dying – including ACP
- Jurisdictional issues (fed & prov), including funding & lack of services
- Lack of communication
- Lack of infrastructure both in terms of human resources (staff & availability) and physical structures (including equipment & resources)
- Lack of education for health care providers, family members and the community as a whole
- Caregiver burnout

# Health System Barriers at EOL

- Communication and language barriers
- Lack of culturally relevant and safe care
- Inadequate hospital discharge planning
- Provincial health system lacks understanding of FNIHB & NIHB policies and procedures (Federal)
- 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 (eg: CCAC, Regional Health Authority)



# Process of PC Program Development in First Nations Communities



# Six Nations of the Grand River Territory



# Six Nations Initiatives

- MOU with HNHB CCAC
- Integration with the Regional Palliative Care Expert Consult Team (HNHB LHIN)
- Advanced Care Planning
- Four Strings Healing Ceremony
- Pilot Project Funding from HNHB LHIN:
  - Partnering with Stedman Hospice
  - Mentorship program for Clinical Nurse Specialist, Psycho-Social Bereavement Clinician, and First Nation Physician
- Local First Nation Palliative Care Expert team providing palliative home care in Six Nations

# Fort William First Nation



# Fort William FN Initiatives

- Journey Mapping Workshop
- Strengthening partnership with Dilico (H&CC provider)
- Community Awareness Sessions (6 sessions with help of community partners: Cancer Centre, CCAC, CERAH, Hospice Northwest)
- Improving Communication and Discharge Planning (TBRHSC, CCAC, & Dilico)
- Community ACP sessions & resource development



# Naotkamegwanning First Nation



# Naotkamegwanning FN Initiatives

- Wiisokotaatiwin Program
  - Proposal for LHIN pilot funding was successful
- Cultural Sensitivity Training Workshop
- Telemedicine (pilot in collaboration with CCO & SJCG)
- Journey Mapping (3 workshops, 24 HCP)
- Advocacy – Federal & Provincial Members of Parliament

# Peguis First Nation





# Peguis First Nation

- Formalizing the Palliative Care Program
- Grief & Bereavement Workshop
- Percy E. Moore Hospital - Doctors Home Visit Initiative and linkage with Palliative Care Nurse and program
- MOU as an engagement strategy

# Research Outcomes

- New Guidelines for Policy/Decision Makers and Practitioners
- Four examples of First Nations Palliative Care Programs, including evaluation of process and outcomes
- New Tools and Resources for Program development and Delivery (including ACP resources)
- Increased collaboration between Federal and Provincial health services
- Advocacy for Gaps in Service (resources, medication, equipment, funding for palliative care)
- Created Palliative Care in First Nations Communities Stakeholder Alliance

# **Recommendations to Improve Quality and Access to End-of-Life Care in First Nations Communities:**

## **Policy Implications from the EOLFN Research Project**

**December 2014**

- 1) Review the current service and equipment levels (essential and supportive services) for federally funded Home and Community Care programs in First Nations and adjust them to reflect:
  - the aging of the population
  - the increased burden of chronic and terminal disease and frailty
  - the increased number of people with high intensity and complex care needs who require home care and intensive case management, especially in the last year of life.

2) Sponsor, support and resource local leaders in First Nations communities to facilitate local community capacity development that would:

- integrate a palliative approach into all community health and social services
- create local palliative care programs using existing services and new partnerships.

### 3) Ensure telemedicine is available in every First Nation community so that:

- people with complex and high intensity needs, especially people who are dying and their families, can receive expert consultation from regional palliative care teams and consultants at home; and
- First Nations' health care providers can receive palliative care education, consultation, and support in their day to day work in the community.

4) Review the current approval process within the Non Insured Health Benefit (NIHB) program to ensure:

- there are “fast track” approval processes for clients in the last year of life, and
- implement Jordan’s principle in any cases of funding disputes across jurisdictions.

# **Framework to Guide Policy and Program Development for Palliative Care in First Nations Communities**



# Overarching Policy Guidelines

- 1) Endorses a ***unique philosophy, definition, and community-based*** process for providing palliative care in First Nations communities that is distinct from a westernized, medicalized or urban model of palliative care.
- 2) Founded on ***collaboration*** across federal, provincial, and territorial jurisdictions that will create equity of access to palliative care for people living in First Nations communities.
- 3) Allows for local ***customization*** of the eligibility criteria for palliative care services and customization of the funding and accountability processes.

# Program Development Guidelines

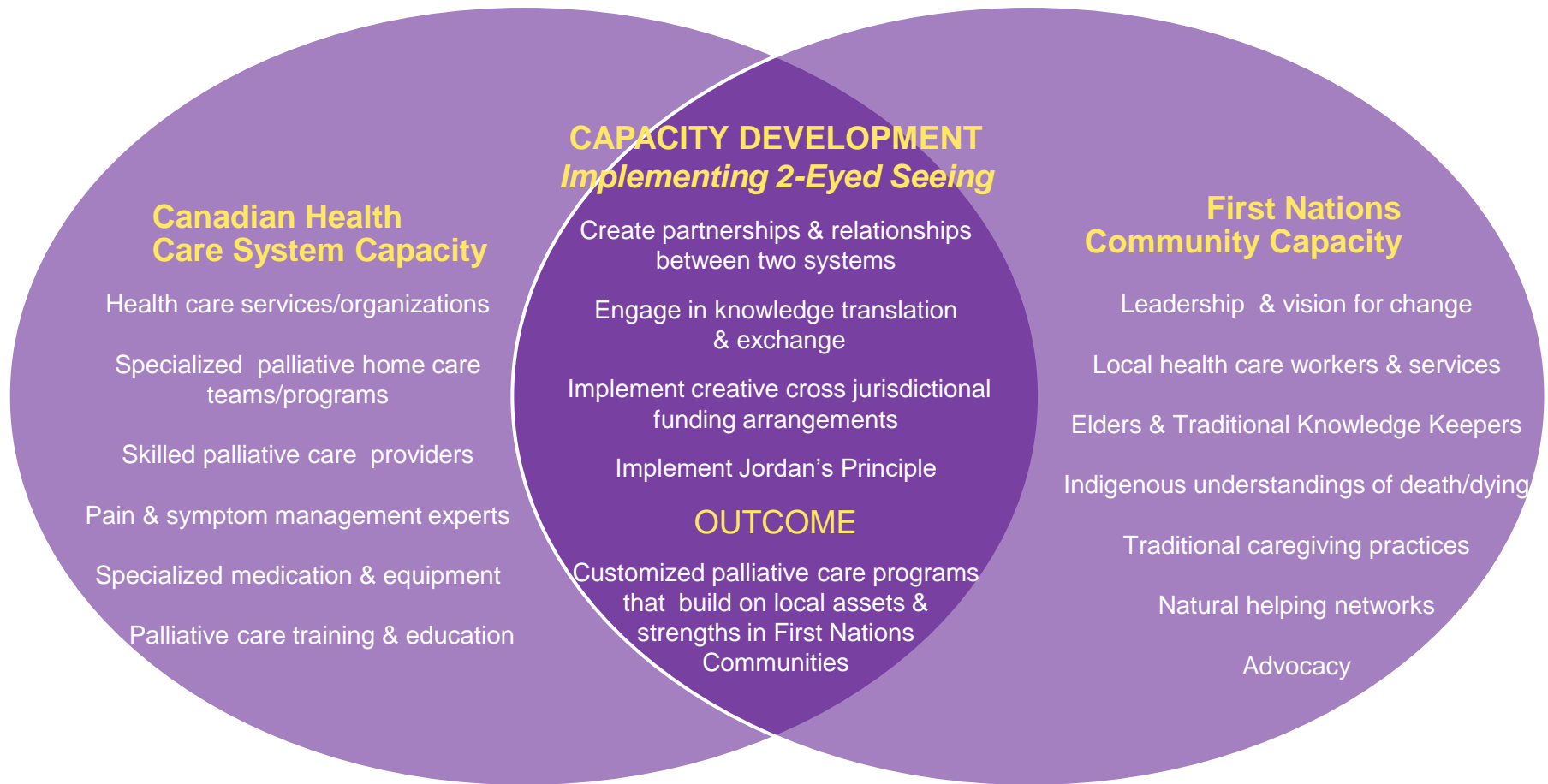
- 4) **Respects** the *integrity* of the each First Nation community, its unique philosophy, and cultural traditions.
- 5) Developed and implemented locally using a “**bottom up**” process of community capacity development.
- 4) Built on *teamwork/collaboration* and *partnerships* across organizations and jurisdictions.
- 5) Provides *access to local home care services at the level required* to support First Nations health care providers, clients, and families.

- 8) Provides access to ***consultant and specialist services at the level required*** to support First Nations health care providers, clients, and families.
- 9) Provides ***education*** related to palliative care and end-of-life experiences for family, community members and for the First Nations health care professionals.
- 10) Offers ***culturally appropriate holistic mental health and grief and bereavement support*** for community members, health care providers, and family, including culture-based support approaches where desired.

# Key Principles

- Definition of Need and Solution (relevant to Context and Culture)
- Community Capacity Development – Highly localized not regionally generalized
- Cultural Competence and Safety
- Local Control and Ownership
- Partnerships between Provincial & Federal funded service(s)/providers
- One size does not fit all (diversity of culture and context)
- Two-eyed Seeing (the best of both Traditional and Western Knowledge)

# Developing Palliative Care in First Nations Communities: Implementing *2-Eyed Seeing*\*



\*Two-eyed Seeing Concept Created by Mi'kmaq Elder Albert Marshall.

Improving End of Life Care in First Nations Community Research Team ([www.eolfn.lakeheadu.ca](http://www.eolfn.lakeheadu.ca)) adapted diagram from the Canadian Institutes of Health Research, Institute of Aboriginal Peoples' Health, Strategic Plan for 2006–2011.

# What is the Model for the Future? A Process ...

- Understand the vision of the Community
- Understand the current Community Capacity: assets, gaps, and barriers
- Create a Work Plan
- Engage Local Health Service Providers
- Empower Local Service Providers to engage and collaborate with External Health Service Providers
- Creating a community accountable local Palliative Care Program (structures & processes are constantly evaluated)
- Monitor outcomes for patients, families, health care providers - at the health systems level

# Contact Information

Dr. Mary Lou Kelley  
Principal Investigator  
Email [eolfn@lakeheadu.ca](mailto:eolfn@lakeheadu.ca)

Melody Wawia  
Research Coordinator  
Phone (807) 766-7274  
Email: eolfn@[lakeheadu.ca](mailto:eolfn@lakeheadu.ca)

[www.eolfn.lakeheadu.ca](http://www.eolfn.lakeheadu.ca)