Healthcare Excellence Canada
Excellence en santé Canada

Enabling Aging in Place Promising Practices: Compassionate Communities

In collaboration with

Health Canada
Santé Canada

The following promising practice was prepared following the Canadian Institute of Health Research (CIHR) Best Brains Exchange event held on October 31 and November 1, 2023. The Best Brains Exchange is an opportunity to gather advice on how to accelerate the uptake of successful models, as well as advice on the policy and knowledge inputs that prioritize continued growth and future sustainability. Healthcare Excellence Canada and Health Canada jointly co-planned the Best Brains Exchange with CIHR. We would like to formally acknowledge the generosity of all participants in sharing their skills, knowledge, expertise and experiences, which were used to inform this promising practice.

About Healthcare Excellence Canada

Healthcare Excellence Canada (HEC) works with partners to spread innovation, build capability and catalyze policy change so that everyone in Canada has safe and high-quality healthcare. Through collaborations with patients, essential care partners and people working in healthcare, we turn proven innovations into lasting improvements in all dimensions of healthcare excellence.

HEC focuses on improving care of older adults, bringing care closer to home and supporting pandemic recovery and resilience – with quality and safety embedded across all our efforts. We are committed to fostering inclusive, culturally safe and equitable care through engagement with different groups, including patients and essential care partners, First Nations, Métis and Inuit, healthcare workers and more.

Launched in 2021, HEC brings together the Canadian Patient Safety Institute and the Canadian Foundation for Healthcare Improvement. We are an independent, not-for-profit organization funded primarily by Health Canada. The views expressed herein do not necessarily represent the views of Health Canada.

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Model background

Sparked in 2013, compassionate communities (CCs) is a global movement dedicated to cultivating collective action and shared responsibility for the caretaking of individuals experiencing hardships, including the experiences of aging, living with serious illness, dying and grieving. Ultimately, the CC concept is centred on the philosophy that communities are an equal partner in the care of individuals and have the necessary knowledge, skills and resources to meet their needs.

The concept of CCs adopts a health promotion approach to palliative care, where aging and dying is viewed as a social experience with a medical component rather than a medical experience with a social component.

The vision for CCs is rooted in the World Health Organization's Ottawa Charter and Healthy City movement, which describes five major pillars of health promotion:

- develop personal skills
- create a supportive environment
- reorient health services
- strengthen community actions
- build healthy public policy

Allan Kellehear championed the adoption of these pillars in palliative care by establishing the first Canadian CC in 2015, proposing that, "the goals of health-promoting palliative care are to provide education, information and policy-making for health, dying and death."

There are now more than 200 documented CCs across Canada. Additionally, four provinces (Ontario, Alberta, British Columbia and Quebec) have organizations supporting provincial-level integration of CCs, and research on CCs is underway in Canada.

Model description

CCs support those with life-limiting illnesses while addressing cultural, psychological, spiritual and social well-being. They do this by strengthening social capital and mobilizing a variety of actors outside of healthcare, such as educational institutions, municipalities, community organizations and faith-based communities.

The objectives of CCs are to do the following:

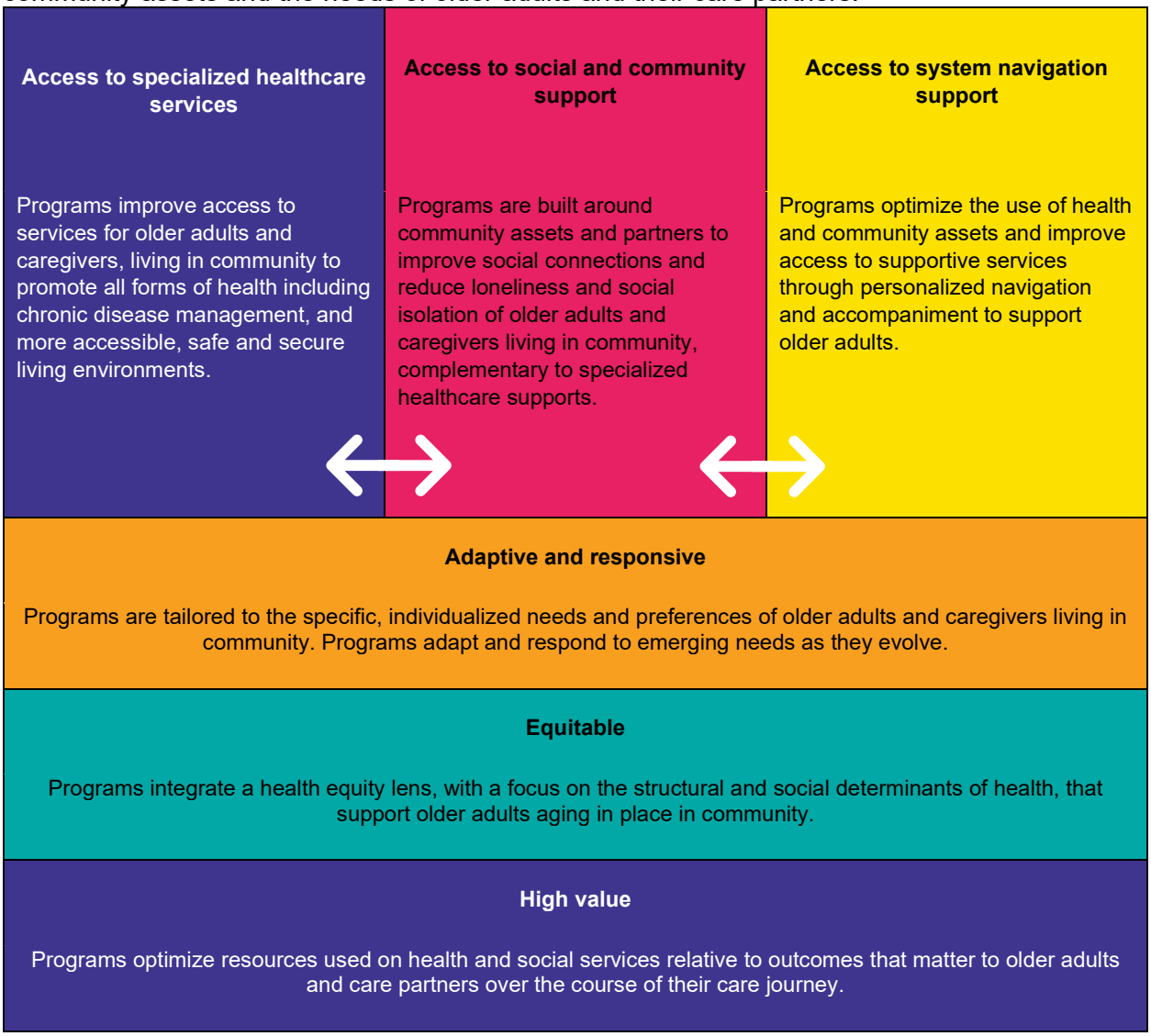
- Connect people who are passionate about and committed to enhancing the experiences of those living with a serious health challenge, caregiving, dying and grieving.
- Accompany people affected by these experiences by connecting them to support services and building supportive networks in the community.

- Improve quality of life for people through mutual aid and practical support within communities.

Ultimately, CCs represent a community-led social model to provide social and practical support for people living with advanced illness – including people's families and care partners. The model inspires, engages and empowers community groups to take an active role in the provision of psychosocial, spiritual and practical supports that aim to improve the experiences and well-being of individuals living in the community.

Enabling aging in place principles

Person-centredness is a core philosophy of HEC's Enabling Aging in Place program. All the principles must be implemented in a person-centred way and reflect a deep understanding of community assets and the needs of older adults and their care partners.



Along the continuum of aging, CCs serve as an end-of-life program rooted in a health promotion approach to palliative care. The following reflects how CCs fulfil HEC's Enabling Aging in Place program principles:

Access to specialized healthcare services – They connect individuals with social and health services, resources and providers to directly support those affected by serious illness, caregiving, dying and grieving experiences.

Access to social and community support – CCs represent a social or relational model that strengthens community capacity-building, resilience and supports by providing opportunities for social connections and care among community members.

Access to system navigation support – Existing at the intersection of health and social services, in addition to informal community services and networks, CCs support formal and informal support system navigation in the community.

Adaptive and responsive – CCs do not represent a brand or prescriptive structure but rather an open-ended, flexible model that enables community self-determination. Communities meet the objectives and vision of a CC by identifying their own creative approach to leveraging their unique knowledge, assets and networks. In this way, they are able to respond to the specific needs, priorities and preferences of their community members.

Equitable – CCs are often focused on addressing health inequalities, diversity and social inclusion. By uniting formal and informal networks, methods, services and resources for responding to individual care needs, CCs better serve groups that traditional services struggle to support.

High value – CCs emphasizes community self-determination and resilience, resourcefulness, the appropriate use of health and social services, as well as the strengthening of social capital, mutual aid relationships and the ability of citizens to actively participate in and lead the development of their communities.

Funding

CCs can be funded in various ways. The amount of funding and the way it is spent is determined by the needs of a particular community where it exists.

Implementation

Assessing needs and assets: Key to a successful CC is community-centricity and self-determination, stakeholder and asset mapping as well as relationship building. In the CC model, community members are centralized in determining their own needs, preferences, priorities, key

actors, leaders, assets and resources. Community members are engaged early and often in the development, implementation and sustainability of CCs.

Program team: As an intersectoral approach, CCs mobilize a variety of civic actors within professional healthcare or social systems (e.g. education, municipalities, community organizations, spiritual groups) and other informal organizations, in addition to individual actors, including patients, family members, neighbours and citizens. Due to the adaptable nature of CCs, teams and leaders may be composed of actors within formal or informal networks as determined by a given community.

Target population: All individuals living within a CC can benefit. CCs intend to benefit general community members and community members facing serious health challenges, caregiving, dying and grieving.

Approach: This unique model for community development depends on deep understanding and strengthening of community assets and requires a different approach than implementing or introducing a new program.

Partnerships: Central to CCs are trusting relationships and partnerships established between community members and diverse local institutions or organizations. For example, Compassionate Ottawa's project site included two community health centres and two faith-based communities, which delivered more than 40 community-led initiatives during the project.

Evaluation and impact[1]

There is robust evidence for the positive individual and system impact of CCs, including improvements in health and wellbeing outcomes and reduced healthcare utilization.

Despite this, community-level evaluation of social models for care delivery can be challenging and limited. Therefore, an opportunity exists to invest in evaluation, which will demonstrate the collective impact of CC.

[1] The evaluation and impact information shared is reflective of information that is currently available at the time of writing this promising practice. HEC would like to acknowledge that evaluation activities are an ongoing process for many promising practices and the type of data collected is influenced by program goals, the length of time the program has been implemented, and the level of resources available to support evaluation.

Keys to success

While CC models vary, the following are general enablers for creating, implementing and sustaining CC initiatives as they relate to community participation, supportive structures, policies and funding:

- Understanding a community's history, contexts, needs, social values and norms.
- Understanding a community's context for social policy and structural conditions in which care is given and received to adapt to local needs.
- Community-led models of care are relational and succeed through chains of trusting relationships which are built over time.
- Engaging communities early and often in CC development and focusing on co-creation, inclusivity and addressing inequities.
- Uplifting hidden change leaders, connectors and builders in the community.
- Creating low barriers to engagement in enabling community members to support one another.
- Building the capacity of CCs for community members, organizations and program teams through training, coaching, learning networks and sharing resources.
- Achieving clarity on governance, as well as the roles and responsibilities of all CC stakeholders, including community members, leaders and organizations.
- Formalizing practical and logistical support by local organizations for community groups.
- Understanding the social and psychological supports necessary for service providers who directly support those who are seriously ill and their families.
- Fostering policies that support intersectoral collaboration and partnerships.
- Developing a CC structure that will ensure sustainability by leveraging existing networks, assets and resources.
- Leveraging research for evidence-informed decision-making in CCs.
- Evaluating CC processes and outcomes.
- Storytelling around the impact of CCs to community members, including ways that partners and community members are recognized and valued.
- Approaching funding innovatively (i.e. pooled funding).
- Remaining mindful of power dynamics in framing conversations around models of care, funding and outcomes with various stakeholders.

Key challenges

While CC models vary, the following are general challenges for creating, implementing and sustaining CC initiatives:

- Lack of public awareness or education about CCs may prevent individuals from getting involved or accessing available resources and supports.
- Resources for measuring CCs are not adapted to or accessible in community contexts.

- Standardized language is lacking from health and social system funders.
- Current approaches to funding (i.e. short time frames, financial sustainability) are not matched to the time it takes to develop relationships, listen to and learn from community experts, implement community initiatives and fully evaluate CC impacts.

Emerging needs

In Canada, elements of the CC model have been implemented in some local and provincial initiatives (e.g. BC Center for Palliative Care), compassionate workplaces, universities, cities and faith community-based initiatives. Examples of the supports these communities provide range from public education to volunteer navigation.

While the movement has grown, uptake has been uneven. There is a short-term need to understand how best to use limited, one-time funding to effectively support the spread and scale of community-led models of care. There is a medium-term need to understand what policy and resource supports are required to enable the spread and scale of compassionate models of care. There is a longer-term need to understand the most pressing policy and evidence gaps so that new knowledge can be generated and shared to sustain the growth and the impact of CCs.

There are opportunities for those supporting the adoption of CCs to do the following:

1. **Enable people to do things differently**
   - Ensure that approaches used to proliferate CCs are fit for purpose.
   - Use organizing approaches that see relationships as structure, process and outcome.
   - Use evidence in a way that supports local assets and solutions (rather than standardization).
   - Emphasize community empowerment with both place-based and system approaches (collective impact tables are one strategy).
   - Improve knowledge translation across funding portfolios and communities, and nationally.
   - Address knowledge gaps.
   - Explore ways to ensure research funders value community-oriented work and support researchers working in this area.
   - Align funding models to better support community organizations.
   - Improve policy supports so they align with and support people in communities (bottom-down policy support).
   - Develop supporting frameworks for funding, policy, knowledge translation and health and social care (including roles for various levels of government).

2. **Expand partnerships**
   - Ask what is both a compassionate and intersectional response to the needs that communities identify and then connect it to work underway whenever possible.
   - Encourage and support researchers and academic institutions to bring together policy

makers, people with lived experience and funders in a collaborative way.

- Explore models such as backbone organizations, pooled funding and collaboration on funding applications to support organizations to work together.
- Use community asset mapping to seek opportunities to engage non-traditional partners and encourage the integration of health and social supports.
- Support community leaders within and across communities with coaching and other resources.
- Be conscious of power relationships.
- Listen to, learn from and better support communities where intergenerational and compassionate care are a way of being (e.g. Indigenous communities, rural and remote communities).
- Raise awareness of compassionate communities.

3. **Measure and evaluate**
    - Ensure the community's definition of success is articulated.
    - Work with communities to develop a core set of common outcomes and then use them to develop indicators/measures that could articulate them.
    - Provide resources and supports to allow deeper evaluation, including qualitative analysis (e.g. process evaluation, experience stories, self-reported data) where possible.
    - Adjust our perspective on data and outcomes so they are meaningful for people, communities, care providers and systems of care.
    - Look for opportunities to better align and utilize the data that is already collected to support communities and tell impact stories.
    - Align outcomes-measurement expectations across funders so the burden of reporting is reduced for communities.
    - Support communities to build evaluation capacity and tailor their messages for the audience receiving the information.

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