



Connecting People & Community for Living Well Partners' Meeting

DATE: November 28, 2023

TIME: 9:30 to 10:30am MDT



WELCOME!
We invite you to write in the chat box
and let us know your...

NAME

LOCATION

ORGANIZATION

We will start shortly

HEALTHY AGING
CORE Collaborative Online
Resources & Education
ALBERTA



AGENDA

- Welcome!
- **Caregiver-Centred Care**
 - Presentation from Jasneet Parmar & Sharon Anderson
- Resources & FYI's
- Next meeting **December 19, 9:30-10:30am MT**



Recognizing Family Caregivers in Asset-Based Community Development

Jasneet Parmar MBBS, MSc, MCFP(COE)

Sharon Anderson, MEd., MSc., PhD

Glenda Tarnowski, Tanya L'Heureux, Michelle Lobchuk, Jamie Penner, Elisabeth Drance, Laurie Caforio, Lesley Charles, Jamie Stewart, Cecilia Marion, Arlene Huhn, Donna Thomson, Laura Schattle-Weiss, Marlene Raasok, Linda Powell, Jim Hnatuk, Sanah Jowhari, Gwen McGhan, Sandra Lundmark, David Howatt, Colleen Turkington, Charlotte Pooler, Johnna Lowther, David Haastrup, Alison McKelvey-Jozsa, Brittany Walsh, and many more

Connecting People and Community for Living Well
November 28, 2023

Objectives

Why support family caregivers?

01

Why?

What supports are needed?

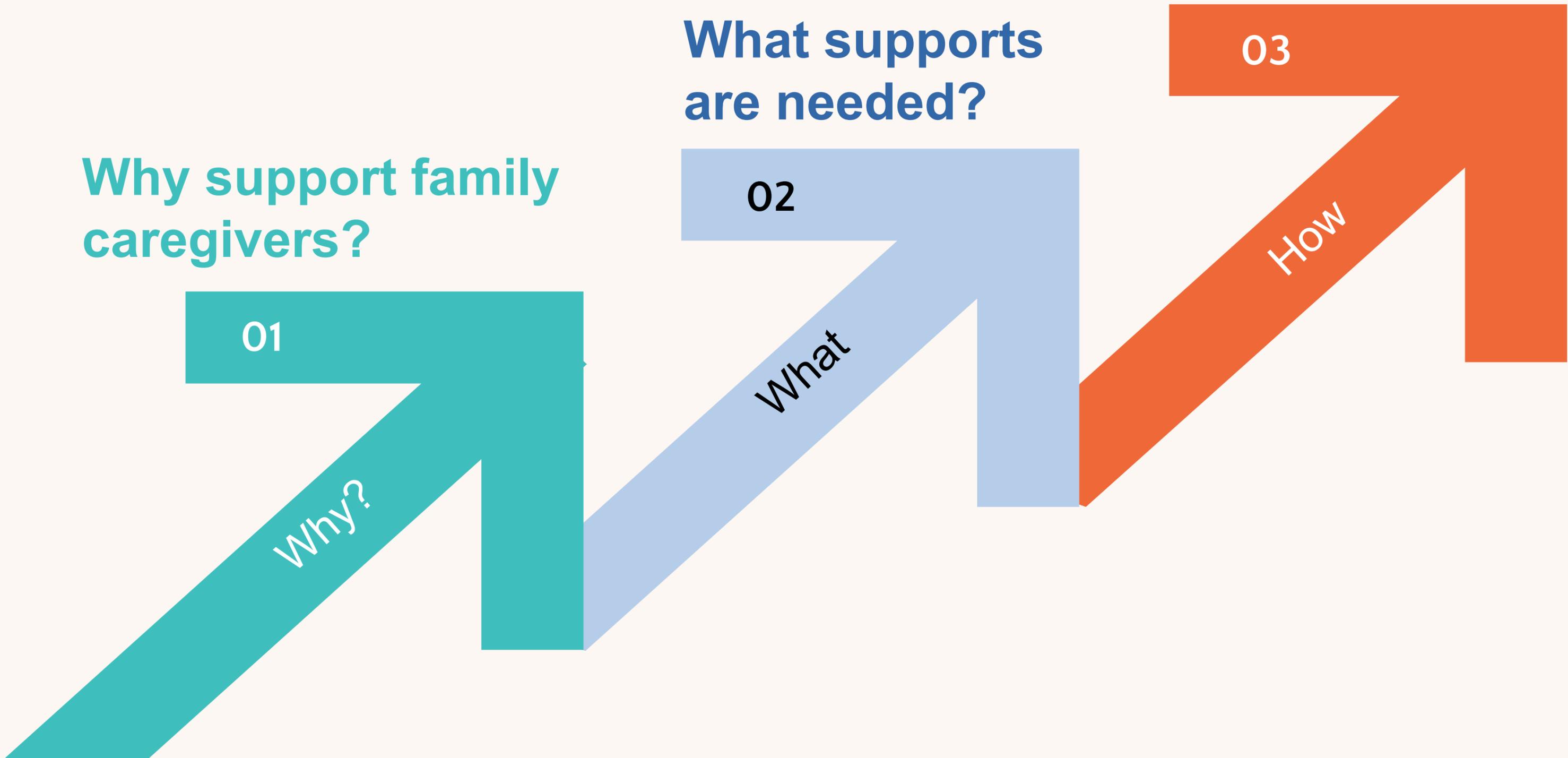
02

What

How can we work together?

03

How





“There are only four kinds of people in the world — those that have been caregivers, those that are caregivers, those who will be caregivers, and those who will need caregivers.”

Family Caregivers: the Invisible Workforce

1 in 4 Canadians are family caregivers
(eventually one in two)

- **Family caregivers support the social connections, dignity & well-being of those they care for.**
- Provide 90% of the care to community-dwelling Canadians needing care & assist with 15-30% of the care in LTC
- Care is worth \$97.1- \$112 Billion yearly.
 - ❖ 32% of Canada's spending on Health!



CAREGIFTING: Caregiving is a gift to the people they care for, the family, the community, and society



Grant Bruno, Samson First Nation,
PhD Candidate University of Alberta

- People needing assistance receive support and care for better health and well-being, which can help them stay engaged in work, volunteer, and family roles as long as possible.
- Caregiving can reduce the need for paid services from health, social services, and transit systems.
- Continued care from family and friends may enable people who need care to remain at home or delay moving to congregate care

Aspirational Caregiver-Friendly Communities

Applying a broad, systems approach to caregiving entails envisioning communities in which:

- All caregivers have the training and knowledge to provide needed care.
- Health and community care providers always involve caregivers on the care team and refer them to supports and services to help maintain their own health (requires provider training).
- Employers institute supportive policies and practices to accommodate all caregivers' needs.
- All caregivers and people living with dementia readily participate in community life and find support wherever they live, work, and play.



Young caregivers



“How do service providers (n=19) working with young caregivers in Canada describe the impacts of the pandemic on themselves, their professional praxis, and on their young caregiver clients?”

- Young caregivers aged 5–25 years
 - Canadian young caregivers spend 14–27 h per week caring (equivalent to a part-time job)
- Significant saving to health system and society.

“Balancing school... a lot of the youth that I supported were full-time caregivers, going to school full time and often were also working part-time or full-time at the same time, so one of the things that was a benefit to young caregivers was online access to school and with that came more flexibility.”

Young caregivers also need our support.

Challenges for Caregivers to Manage

1 CARE

Assistance with personal care, instrumental and extended activities of daily living tasks

2 Medication

Keeping track, ordering, organizing & storing, understanding dose/ side effects.

3 Medical Appointments/Care

Coordinating, Attending, Transporting, monitoring, crisis

4 Emotional burden

loss of health, personal autonomy, relationship.

5 Physical Burden

Lifting, carrying, bending.

6 Being on-call

- Most of the day & night
- Assumption FCGs are available, able, and willing to take on the burdens & responsibilities of supporting patients

7 Out-of-pocket costs

Medication, driving to medical appts, parking, food away from home.

8 Structural Burden of Care

Assuming roles of project manager & care coordinator

9 Setting aside one's own needs

Losing one's sense of identity
Losing other roles

Linda Powell

Family Caregiver



Caregiver-Centered Care Education

I did not realize the number of providers it would take if there were no family caregivers. The healthcare system is so strained, and it's pouring onto the general public and there needs to be a better way to support family caregivers.

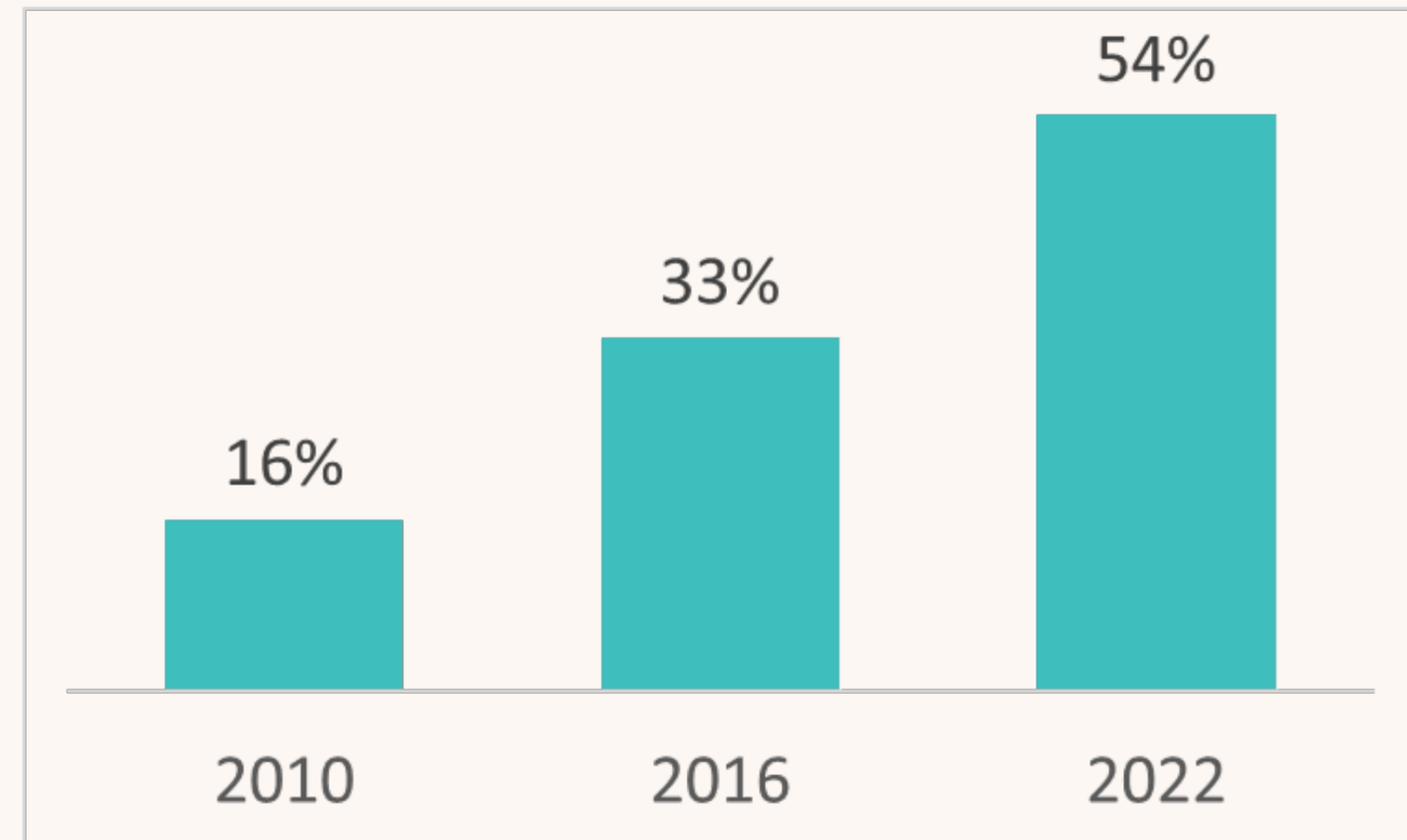
Excellent education! I believe that the healthcare team often puts family caregivers on the sidelines. After finishing this module, I realized how much input they can give us to improve the quality of care we can provide to the care recipient.

www.caregivercare.ca

Rising Family Caregiver Distress

Anxiety most frequently occurring disorder in caregiving

- typically rises as care responsibilities increase & energy is depleted.
- Increases risk of heart disease, dementia, & premature mortality.**



Fewer Family Caregivers

- Smaller Families
- Women employed
- Changed family structure

Longer Care Trajectories

- Longer lives
- More chronic conditions
- Medical advances

Aging in Place

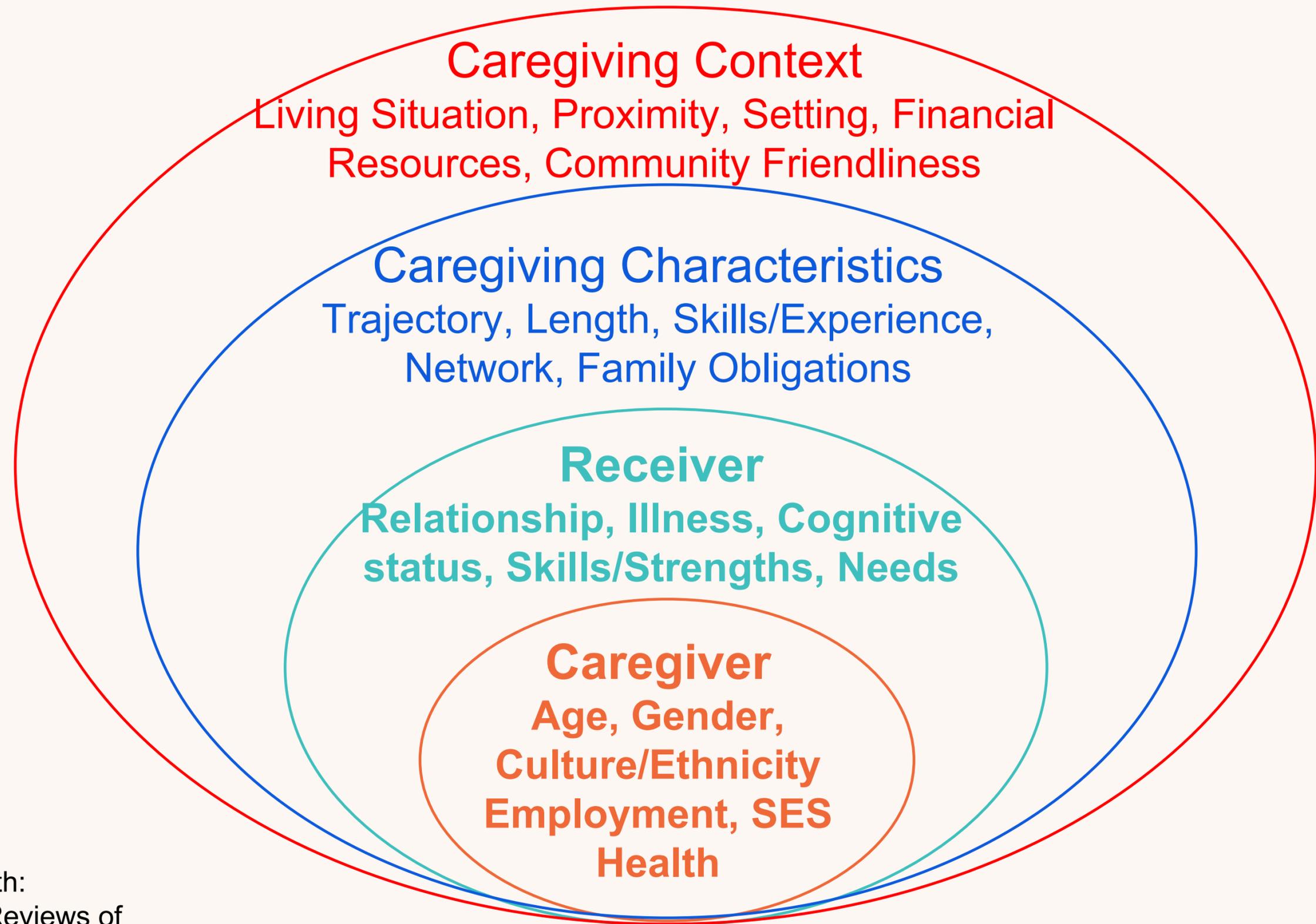
- Prefer community homes
- Fewer long-term care beds

**Vytal, et al. The complex interaction between anxiety and cognition: insight from spatial and verbal working memory. *Frontiers in Human Neuroscience* 2013, 7, doi:10.3389/fnhum.2013.00093.

(Bookman & Harrington, 2007; CIHR: Supporting Caregivers, 2010; Health Quality Ontario, 2016)

Family caregivers are diverse.

- There is no one-size-fits-all solution to meet the needs of Canada's 8 million family caregivers. No single provider or organization is likely to meet caregivers' diverse needs over the entire care trajectory.



An Integrated System to Support Family Caregivers

1. Recognize Caregivers

All systems must support system-level changes to formally recognize caregivers, and incorporate them into care plans.

2 Integrated Community and Health Care

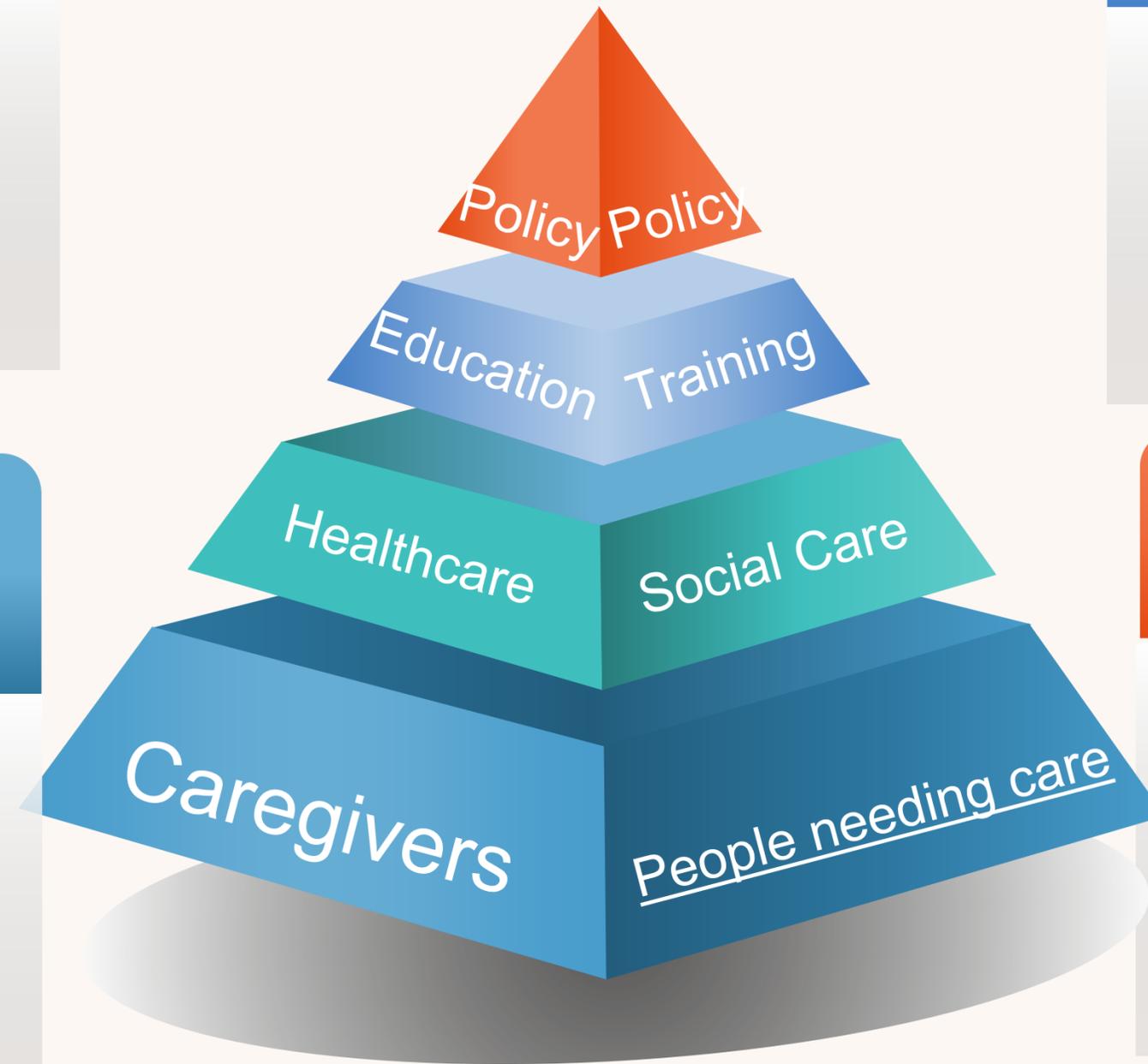
Community and Health systems must develop robust partnerships with community programs & organizations that support caregivers.

3. Education

Incorporate education on caregiving & integrated care into providers' education

4. Policy

Need broad, coordinated scale-up of policies to support caregivers as part of strategy to improve caregivers and recipient wellbeing outcomes.



Biggest Gap in Support for Family Caregivers

In most models of health and community care, family caregivers are underrecognized, under-supported, and overused.

Few health or community care providers have received training in caregiver engagement, and typically there is a reluctance to collaborate with caregivers and an unwillingness to involve caregivers in the care process in a meaningful fashion.

Often, they don't engage caregivers due to lack of confidence, uncertainty about how to assist, or limited time.



Nickell et al. 2020 Effect of an innovative model of complexity care on family caregiver experience Canadian Family Physician <https://www.cfp.ca/content/cfp/66/3/194.full.pdf>

Caregivers Alberta Johnna Lowther. Janis Miysaki



Caregiver-centered care is person-centered care for family caregivers.



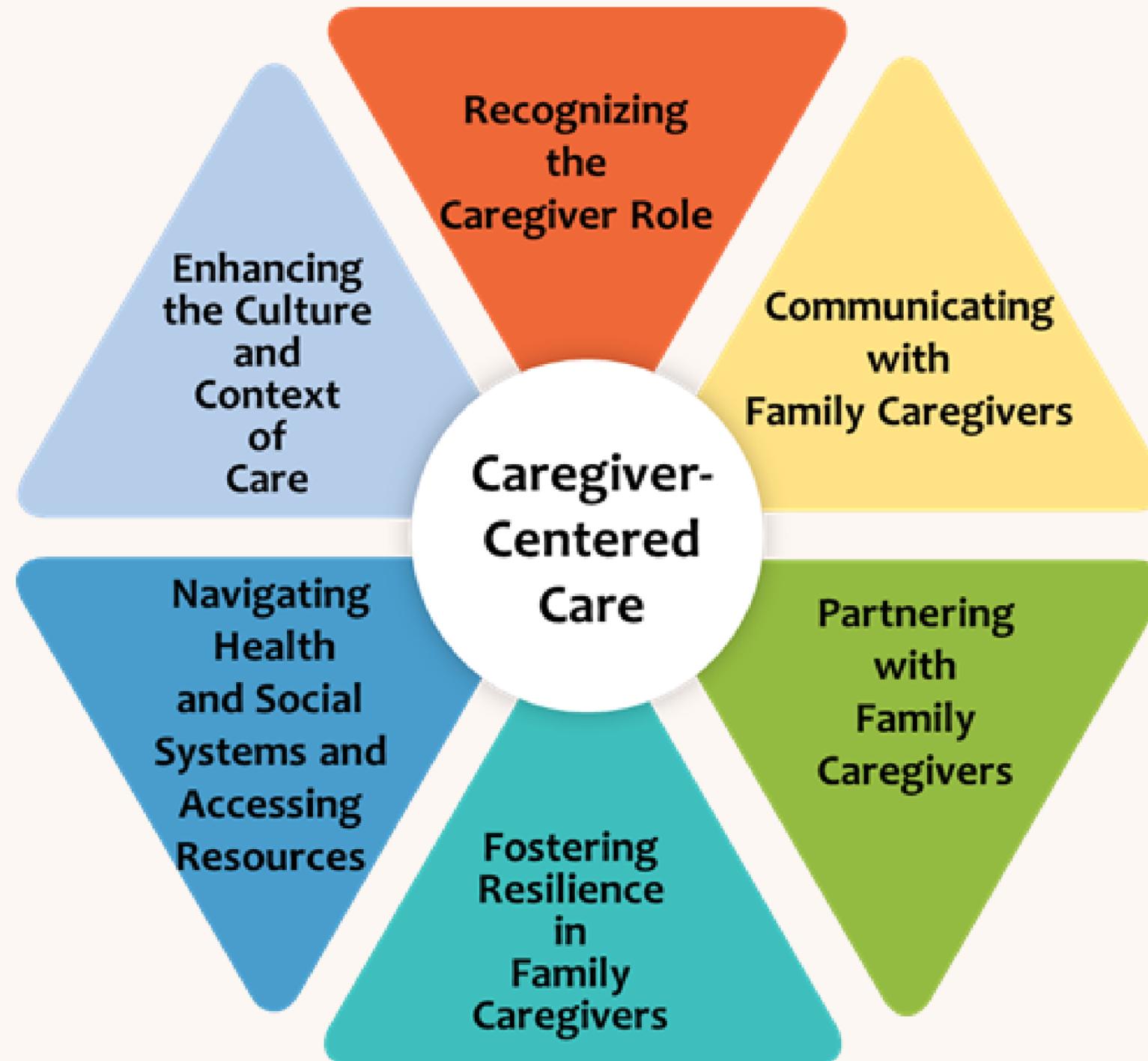
Caregiver-centered care is an approach to healthcare and support services that places a strong emphasis on recognizing and addressing the needs, well-being, and experiences of caregivers who provide care for individuals with chronic illnesses, disabilities, or other healthcare needs.



"Caregiver-centered care" specifically highlights that caregivers play a crucial role in the overall care and well-being of the people they care for, caregivers' importance, ensuring they're seen as vital collaborators alongside health and social care professionals.

Parmar, J. et al. Developing person-centred care competencies for the healthcare workforce to support family caregivers: Caregiver centred care. *Health Soc Care Community* 2021, 29, 1327-1338, doi:10.1111/hsc.13173. (email us for the paper, it is not open source)

Caregiver-Centered Care Competency-Based Education



- A** SSET
- B** ASSED
- C** COMMUNITY
- D** DEVELOPMENT

Co-Design: Nothing about us without us

Fully comprehending stakeholders' needs and wishes is impossible without designing with them.

Co-design refers to the active involvement of people with lived experience and other stakeholders in design processes.



Three Competency Levels

Champions Education

Healthcare providers who model and mentor caregiver-centered care.

Caregiver-Centered Care
Champions

Advanced Education

Healthcare providers with more interactions with family caregivers or significant responsibility for caregivers in role and context.

Advanced Level
Caregiver-Centered Care
Some Health Providers

COVID-19 Education

Specialized Education on Crisis Management

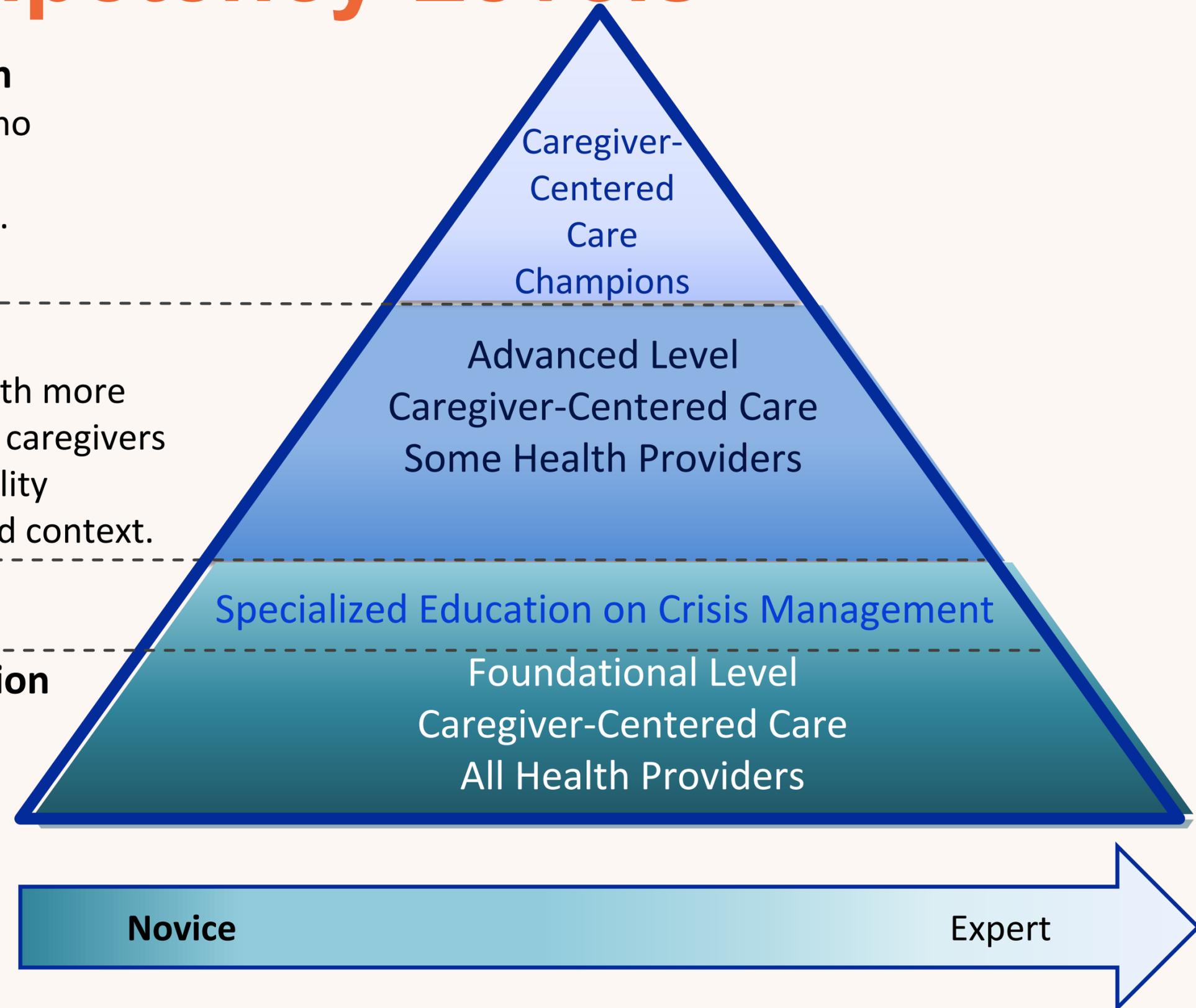
Foundational Education

Healthcare providers who interact with family caregivers in role and context.

Foundational Level
Caregiver-Centered Care
All Health Providers

Novice

Expert



Caregiver-Centered Care

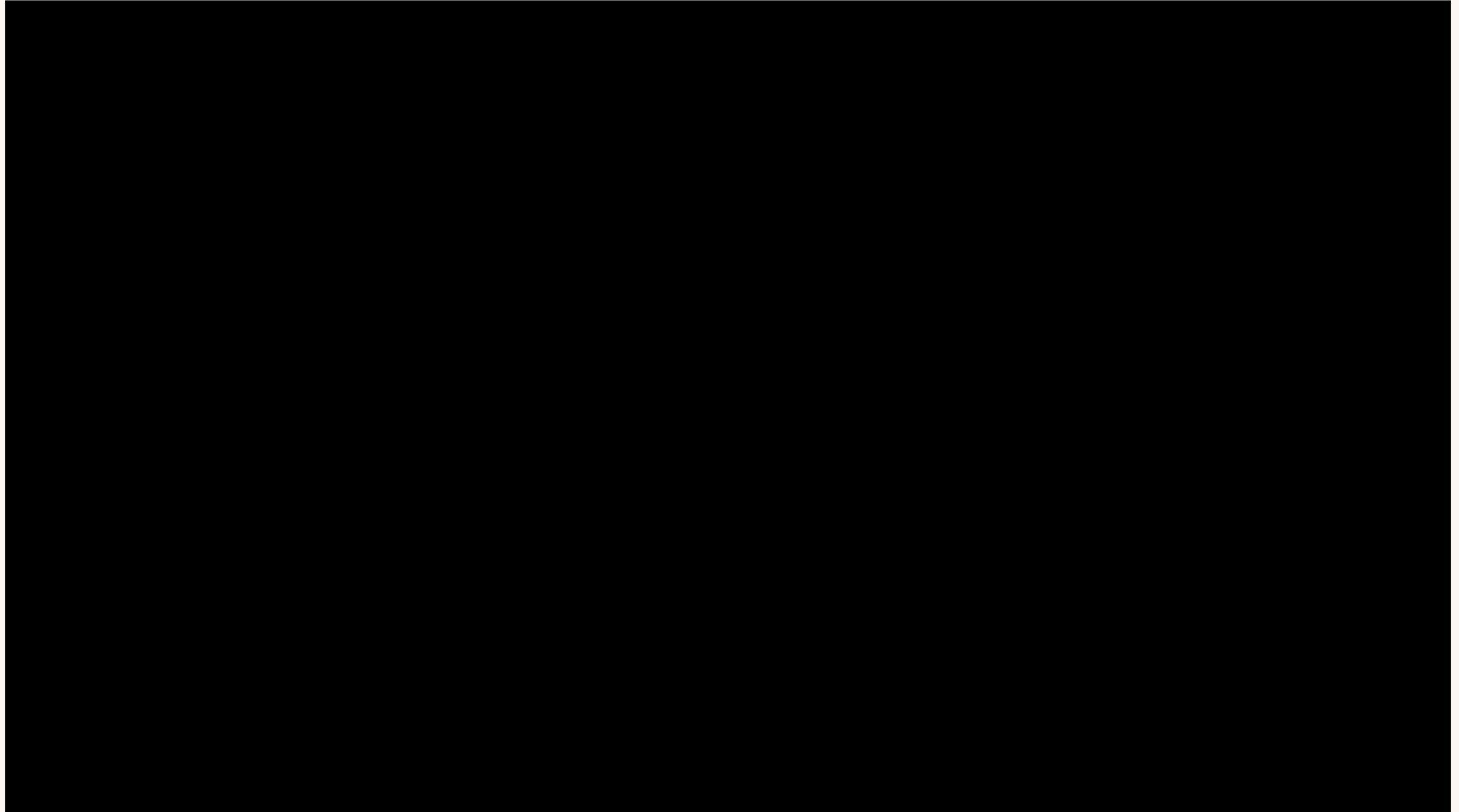
FOUNDATIONAL COURSE

COVID-19 EDUCATION

ADVANCED EDUCATION

Free online at [Caregivercare.ca](https://www.caregivercare.ca)

A taste of the Caregiver-Centered Care Education: Foundational Education



Caregiver-Centered Care Education

I enjoyed the opportunity to practice my conversations with the multi-media and getting to choose what I would say next. This was brilliant!

The videos where you choose verbal responses was really helpful in providing examples of language to use.

The healthcare system will fail without family caregivers. Working as a team to meet the needs of the family caregiver, the system is creating a better care environment.

www.caregivercare.ca

Education and training are recognized strategies to bolster evidence-based practices and change the culture and context of care.



Waltz, T.J.; Powell, B.J.; Matthieu, M.M.; Damschroder, L.J.; Chinman, M.J.; Smith, J.L.; Proctor, E.K.; Kirchner, J.E. Use of concept mapping to characterize relationships among implementation strategies and assess their feasibility and importance: results from the Expert Recommendations for Implementing Change (ERIC) study. *Implement Sci* 2015, 10, 109, doi:10.1186/s13012-015-0295-0.

Dolcini, M.M.; Davey-Rothwell, M.A.; Singh, R.R.; Catania, J.A.; Gandelman, A.A.; Narayanan, V.; Harris, J.; McKay, V.R. Use of effective training and quality assurance strategies is associated with high-fidelity EBI implementation in practice settings: A case analysis. *Translational Behavioral Medicine* 2021, 11, 34-45, doi:10.1093/tbm/ibz158.

Caregiver-Centered Care Education

This was great. I did not know we had such a resourceful module for health and community care providers.

Most relevant course I've taken so far this year.

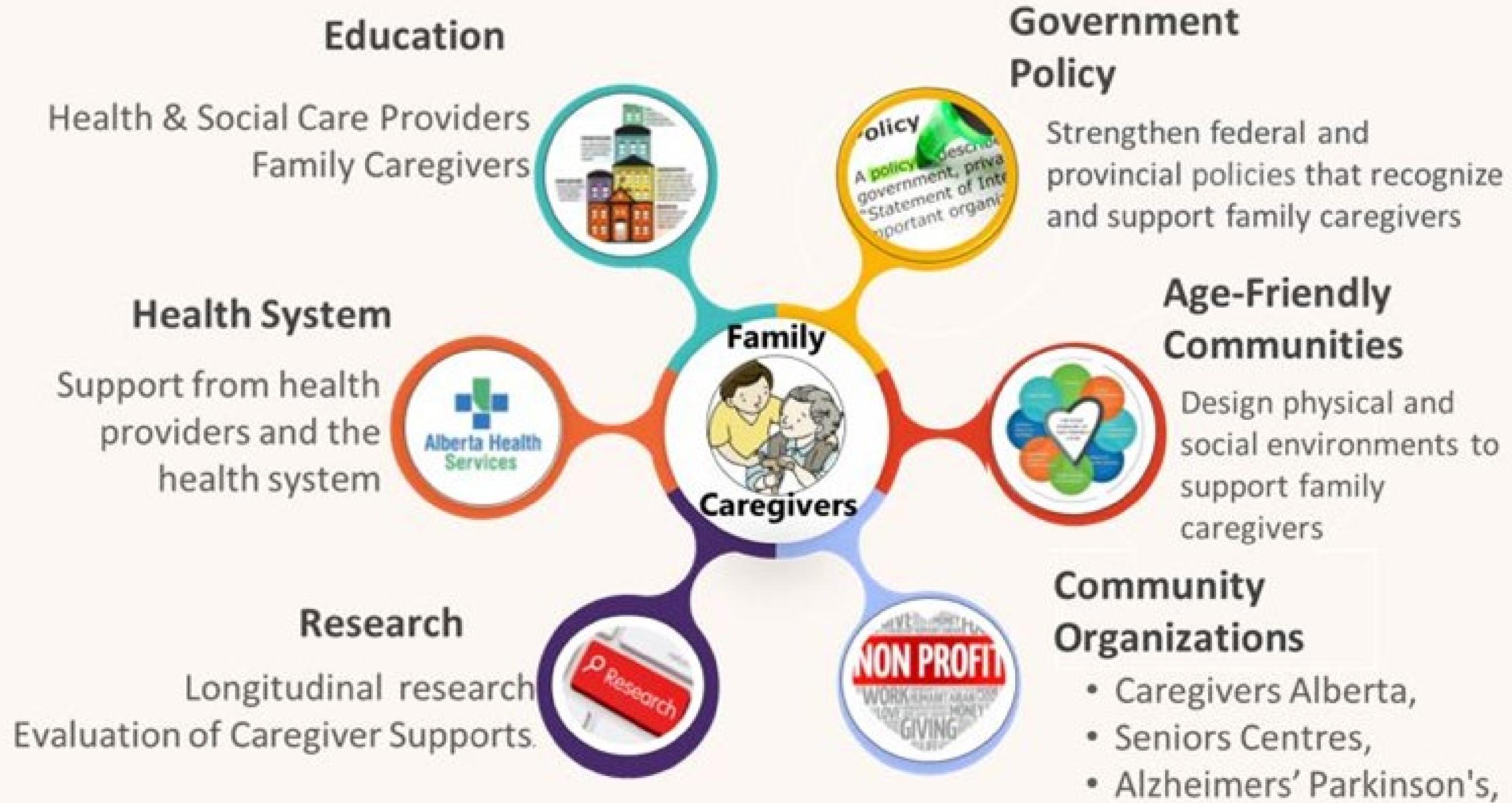
This education should be part of the curriculum in all professional roles. It is an amazing course, thank you.

www.caregivercare.ca

78% of Edmonton Zone Palliative Care Team
have taken the Foundational Education



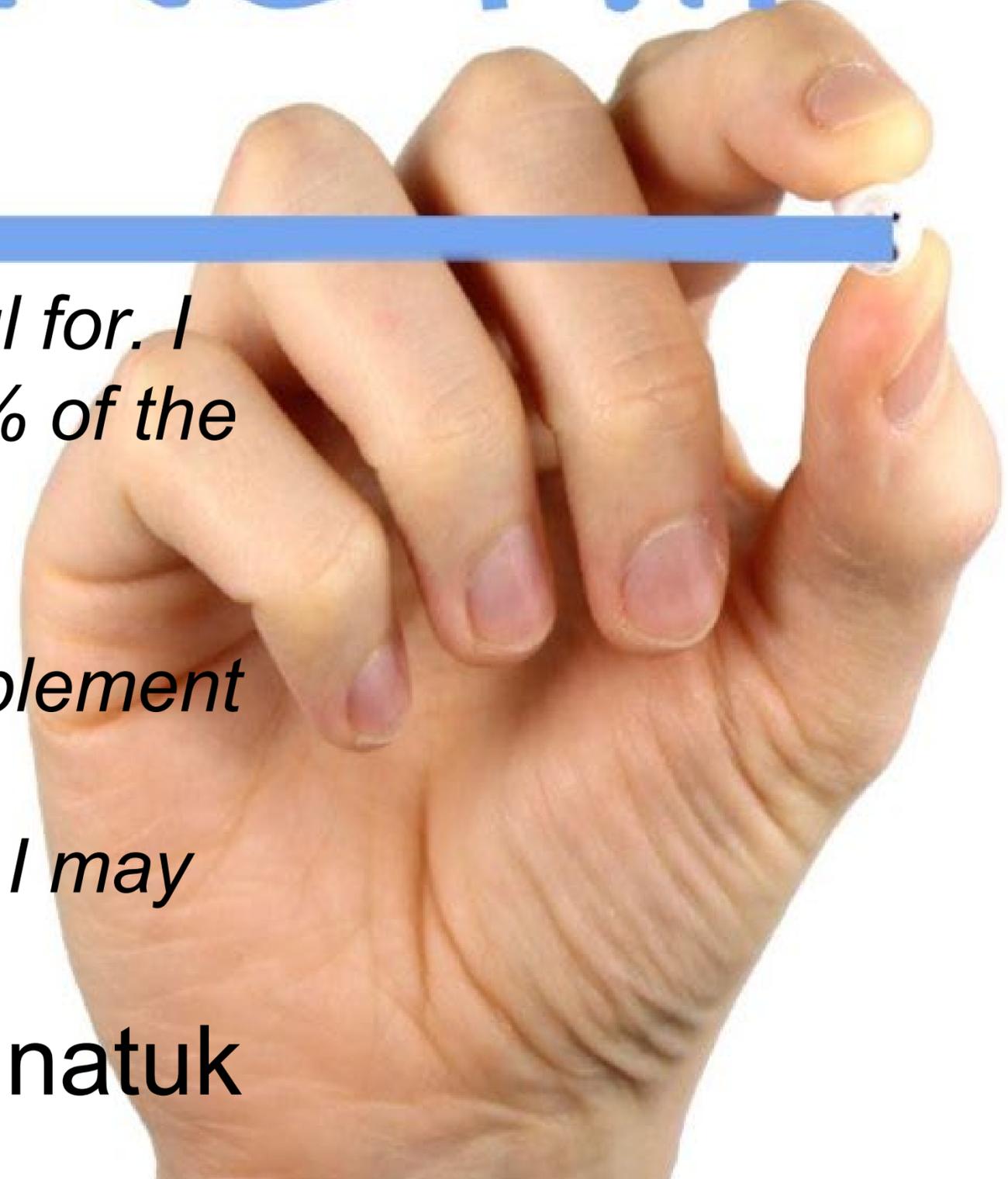
Collective Impact: Collaboration at Micro, Meso, Macro Levels



Zarit, S.H. Past is prologue: how to advance caregiver interventions. *Aging Ment Health* 2018, 22, 717-722, <https://bit.ly/3tBlmKp>

Schulz, R.et al.. Changing Structures and Processes to Support Family Caregivers of Seriously Ill Patients. *J Palli Med* 2018, 21, S36-S42, <https://bit.ly/3Q739em>

PARTNERSHIP

A close-up photograph of a hand holding a blue highlighter pen. The hand is positioned on the right side of the frame, with the thumb and index finger gripping the pen. The pen is held horizontally, with the tip pointing towards the left. The background is plain white.

I have gotten a lot of help that I am grateful for. I do not believe that Caregivers provide 90% of the care. I am not a Priest, Medical Doctor, Psychologist, Dentist, or Psychiatrist I provide as much care as possible to supplement what is available.

Some days that may be 100%, other days I may be a spectator.

Jim Hnatuk



1. Are you identifying family caregivers and including them in planning?
2. Does your asset mapping include who is available to support Family Caregivers?
3. Are the providers who work with family caregivers taking the Caregiver-Centered Care Education?
4. Are Caregiver Champions embedded in your teams?

Questions?



Thank You

Caregiver-Centered Care
Caregivercare.ca

Contact

Jasneet Parmar: Jasneet.Parmar@AHS.ca

Sharon Anderson: sdanders@ualberta.ca

RESOURCES & FYI's

- **[Beyond the Walls: Partnering with People and Communities to Achieve Health](#)**, with Cormac Russell

In this keynote presentation delivered as part of AHS' Patient and Family Centred Care Week 2023 celebrations, Cormac Russell spoke about how communities and citizens are co-creators of health and how our health systems can be better guests in the lives of people and communities we serve.

- **Podcast: [The Connected Community](#)**, with Cormac Russell and Sacha DeWolfe

This podcast seeks to highlight people across the world in various fields who are working, discovering, and thriving in community spaces. Through this celebration and coming together we hope that people reimagine community as the driver of the Good Life.

- **[How to be a dementia friend](#)**

The Dementia-Friendly Canada project, led by the Alzheimer Society of Canada, describes a dementia-friendly community as one where people living with dementia, their families and care partners feel included and supported. How to be a dementia friend describes how individuals and organizations can promote dementia-friendly principles and make meaningful changes in their community and/or workplace.

- **[COURAGE Action for Better Aging Report](#)**

Canadians have made their wishes clear. We want to stay in our homes and communities as we get older. We want the opportunity to maintain our freedom, self-worth, identity, and comfort. We want to play active roles in our community and have the independence, choice and supports we need to live full lives connected to everything we love.

WEBSITE: www.ahs.ca/cpclw

Connecting People & Community for Living Well

Transforming local care and supports to build and sustain wellbeing



Our team works provincially with rural multi-sector community teams to build and sustain the wellbeing of local underserved populations such as seniors impacted by dementia, and others who may benefit from enhanced support within their community.

[At-a-Glance](#)

[Model & Resource Bundle](#)

[Our Team](#)

[Progress to Date](#)

Featured

CPCLW [final evaluation report and summary](#) now available

Highlighting outcomes for five Alberta communities, factors influencing wellbeing, implementation processes, impacts and lessons learned

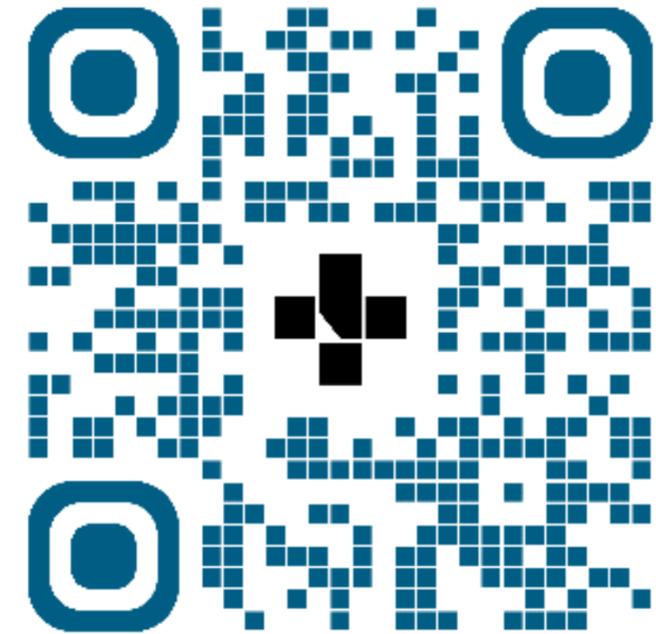
Local Stories & Case Studies

Examples of community partnerships, action and successes across Alberta.

[More >](#)

Evidence of Impact

- [Activities & impact infographic \(2020-2022\)](#)
- [Applied Research Summary, Health Canada Grant \(2023\)](#)
- [CPCLW final evaluation report & Summary \(2023\)](#)



- Email us at: cpclw@ahs.ca
- Visit our website at: www.ahs.ca/cpclw
- View our playlist on [Healthy Aging Alberta - YouTube](#)

JOIN US ON HEALTHY AGING CORE ALBERTA

<https://corealberta.ca>

The screenshot displays the website's header and main content area. At the top left is the logo for 'HEALTHY AGING CORE ALBERTA Collaborative Online Resources & Education'. To its right is a dropdown menu set to 'CORE Alberta' and a search bar. Further right are a globe icon, a 'LOG IN' link, and a 'SIGN UP →' button, which is highlighted by a red arrow labeled '1'. Below the header is a dark blue navigation bar with links for 'Home', 'Groups', 'Funding Opportunities', 'Network Partners & Organizations', 'Resources', 'Training & Events', and 'News'. The 'Home' link is highlighted by a red arrow labeled '2'. The main content area features a large hero image of people at a table with the text 'Healthy Aging CORE Alberta'. Below this is a sub-header: 'The knowledge hub connecting organizations that support and advance independent living for older Albertans', followed by a 'SIGN UP →' button. On the right side, there is a featured community group card for 'MC MI NK +21' with a '+ JOIN' button, highlighted by a red arrow labeled '3'. The card title is 'Connecting People & Community for Living Well' and the description begins with 'Connecting People & Community for Living Well is a provincial initiative within Alberta Health Services that...'. A partial 'Are info help' link is visible at the bottom of the card.

CONTACT INFORMATION

Sharon Hamlin
Senior Practice Consultant
Sharon.Hamlin@ahs.ca

Helen Lightfoot
Senior Practice Consultant
Helen.Lightfoot@ahs.ca

Aleksandra Tymczak
Research Coordinator
Aleksandra.Tymczak@ahs.ca

Katie Mellon
Provincial Practice Lead
Katharine.Mellon@ahs.ca

Blair Wold
Provincial Practice Lead
Blair.Wold@ahs.ca

Kate Hoang
Project Coordinator
Kate.Hoang@ahs.ca

Mikie Mork
Executive Director, Pan-SCN
Mikie.Mork@ahs.ca

Karenn Chan
Care of the Elderly Physician
kchan1@ualberta.ca

Laurel Scott
Advisor
Laurel.Scott@ahs.ca

