



ALBERTA ASSOCIATION ON GERONTOLOGY

# Futures Policy Forum

*Transforming Healthy Aging and Quality of Life  
for Older Albertans*

## VALUING CARE AND FAMILY CAREGIVERS



**Webinar 6 Summary Report for Stakeholder Collaborative Committee,  
February 15, 2023: Webinar Overview, Reach, Participant Experience,  
What Matters to Participants, Summary Observations**

## 1.0 WEBINAR 6 OVERVIEW

### 1.1 Objectives

- To ground thinking and planning for a transformed system of services for healthy aging and quality of life for older Albertans with a call for action to value care and family caregivers
- To learn about data on the value of family caregivers and the importance of recognizing family caregivers' work
- To learn about strategies to support family caregivers as Alberta moves to integrate care closer to home, informed by Alberta Health Services and Caregivers Alberta
- To provide opportunities for participants to express their views and priorities related to valuing family caregivers in the transformation of seniors' services.

### 1.2 Presenters and Themes (NOTE: Infor based on video recordings & slides; speaker consents in place supporting use of information by AAG)

**Webinar Chair, Sharon Anderson introduced the Webinar, underscoring its importance given the vision of Alberta's transformation plan to enhance healthy aging and quality of life for older Albertans with importance across the three tier of policy action.**

- Family caregivers is the term being used for persons who are kin or friends for recipients of care/support and who are providing unpaid assistance.
- Over 93 % of older adults live in the community, and the majority of Albertans want this future; the balance of the population, persons with higher care needs are supported in continuing care homes.
- One in 4 Albertans provide support for family or friends who are recipients of care or need support to live independently. Recipients of support may be children, adults and older adults.
- Family caregivers are diverse: they come from all age groups; may be working and providing unpaid care at the same time; may be retired; and come from a diversity of ethnic backgrounds.
- Our challenge: valuing care as much as cure; valuing family caregiving as a formal part of community & health care supports; building a system to support family caregivers with an integrated, collective impact approach.

**Speakers shared their research knowledge and experiences to create a foundation for this important area for policy and practice development.**

- **Jane Badets, Senior Policy Adviser for Statistic Canada spoke to the topic, "What is the care economy".**
  - *Canada's care economy is defined as the sector of the broader economy comprising the provision of paid & unpaid care work that supports the physical, psychological, and emotional needs of care-dependent persons.*
  - *Caregiving is the next frontier of public policy in Canada, with the challenge of the invisibility of unpaid work.*
  - Population trends have major implications for how care is delivered. Future planning needs to consider impact of immigration, differing cultural expectations, and changes in family structure e.g., smaller families, adult children living at a distance from parents, higher rates of employed working age adults, older households, diversity of living arrangements which may decrease supply of paid and family caregivers.

- Statistics Canada has developed a Care Economy conceptual framework for policy considerations and is now working on systems to collect data regarding the scope of paid and unpaid care work.<sup>1</sup>
- **Dr. Janet Fast, Professor U of A, spoke to the topic, “Making caregiver’s contributions visible, valued & sustainable”.**
  - *Invisibility of family caregiver’s care work has negative implications: 1) this care work is often viewed as “free labour” which contains the costs in the formal system; 2) it is seen as supplemental to the formal system when it is really the formal care that is supplemental to family care work; and 3) reluctance to account for family caregiver’s contributions.*
  - *Caregiving statistics for Alberta show the impact:*
    - ✓ *1 in 4 (1 million) Albertans are family caregivers- 84% have personal connections; 16%, non-kin*
    - ✓ *Estimated amount of support: 15 hours/week (equivalent to 2 days FTE)*
    - ✓ *Estimated value of support: \$12 Billion/year based on hiring replacement workers, equivalent to 1/3 of total health care spending in Alberta (2021)*
  - *Inequities in care: the family caregivers punching above their weight include women, lower income individuals, co-residents with receivers, baby boomers.<sup>2</sup>*
- **Dr. Richard Lewanczuk, AHS Senior Medical Director for Health System Integration:**

**“Supporting Family Caregivers as Alberta Moves to Integrated Care Closer to Home**

  - *Spoke to “roads well-travelled”: for sustainability, we must address avoidable health care costs related to hospital stays resulting from unmet needs for support, e.g., supports not available in the community or in people’s homes on return from hospital.*
  - *Four provinces ask the patient if they have a family caregiver and record the family caregiver on the chart. Alberta does not.*
  - *Spoke to the challenges of “roads less travelled” (RE-AIM Quintuple aim): improving the quality of the care experience; health equity; clinician wellbeing; and the pursuit of better health, improved outcomes, and lower costs. Need to partner with Albertans and communities.*
  - *Working with family caregivers means thinking and acting on system barriers and improving community supports for caregiver wellbeing.*
- **Johnna Lowther, Director Programs & Services for Caregivers Alberta**
  - *spoke to the diversity of caregivers served by their organization: family of young disabled , older adults , long-distance care givers, individuals with jobs and caregiving responsibilities.*
  - *they offer a range of services with the goal of early intervention for family caregivers to reduce negative health impacts (fatigue, intensive caregiving, heavy lifting, depression, ill health) and negative financial impacts (missing work, financial hardship).*
  - *they have resources to help family caregivers find community-based supports.*
  - *organization focus: Supporting Caregiver’s Wellbeing: By caregivers for caregivers. Acknowledged support from Alberta Health for certain programs.*

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<sup>1</sup> See Statistics Canada The Daily for July-August 2022 Survey: More than half of women provide care to children and care-dependent adults in Canada, 2022 <https://www150.statcan.gc.ca/n1/daily-quotidien/221108/dq221108b-eng.htm>

<sup>2</sup> See Infographics: *Value of family caregiving in Canada, Who are employed caregivers in Canada? in English and Qui sont les aidants en emploi au Canada in French, 2022 How does caregiving impact paid work for employed women and men? in English and French on Quelles répercussions les soins ont-ils sur le travail rémunéré des femmes et des hommes? available on Dr. Janet Fast and Research on Aging Policies and Practices website: <https://rapp.ualberta.ca/snapshot-of-aging/>*

As a concluding question for the webinar, all speakers were asked where a final question regarding a better future for family caregiving: Wouldn't it be wonderful if:

- a. We had more financial support for caregivers.
- b. We recognized family caregivers across the system –as integral to service & care delivery, building on a strong Caregivers Alberta as a provincial champion and system connector.
- c. We can address data gaps so we can account for unpaid care work and use this to plan.

## 2.0 WEBINAR REACH

### 2.1 Webinar Registration and Attendance

- **156 people attended the webinar.**
  - **Attendance remains high, with this 6<sup>th</sup> Webinar maintaining attendance @ 150**
  - Unfortunately, attendance at the webinar was reduced due to a concurrent event by Alberta Health (An Innovation Summit); initial plans for concurrent delivery of this webinar at this event were not being feasible.
  - Reasons for No Show were primarily related to personal scheduling challenges.
- NOTE: Registrants who are unable to attend have access to speaker slides & the video recording within days of the event for their own use according to their schedule.

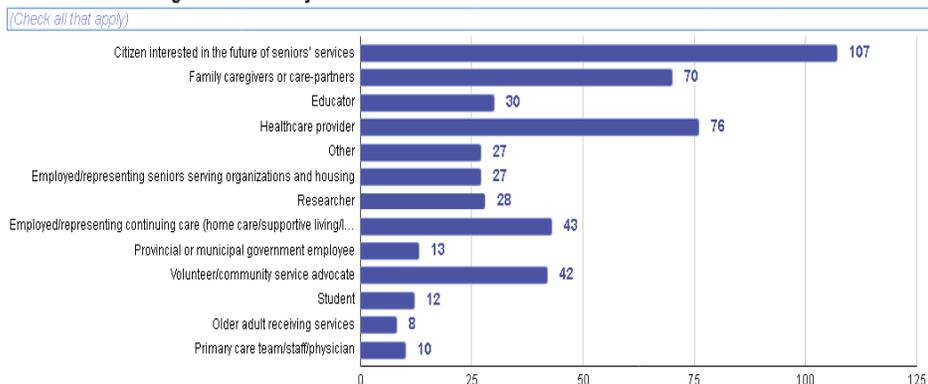
### 2.2 Geographic Coverage

- Most participants were from Edmonton (39%), Calgary (31%) followed by Sherwood Park, Lethbridge, St. Albert, Red Deer, High River, Medicine Hat—in keeping with population distribution in the province.
- Attendance includes individuals from across the province.

### 2.3 Affiliation of Attendees

Which of the following best describes you?

*(Check all that apply)*



- **It is encouraging to see great diversity of attendance, with high percentage of citizens interested in *the future of seniors' services as well as health care providers and staff.***

### 2.4 Summary re: Reach

Webinar #6 demonstrates the power of this medium in reaching a broad audience.

The diversity of attendance is encouraging given the topic and the importance of engaging a wide range of citizens and organizations to understand these new directions & opportunities to be involved in the way forward.

### 3.0 WEBINAR EXPERIENCE, PER POST-SURVEY QUESTIONS

- **34 responses as of February 8<sup>th</sup> (22 % of attendees, typical of previous response rates)**

#### 3.1 Value of the Webinar

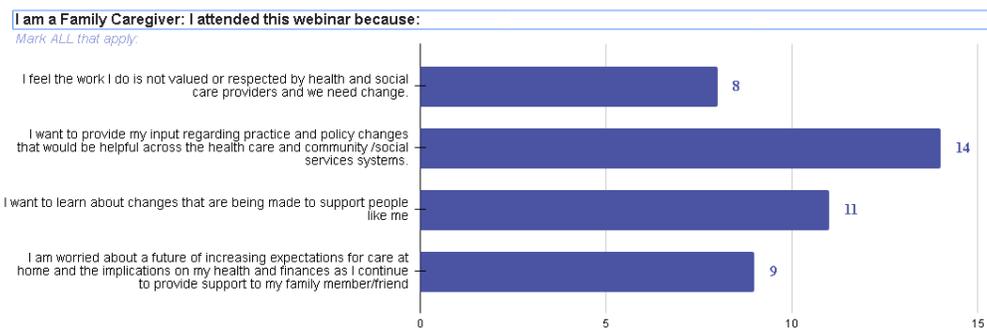
- **Participation in Webinar**
  - Most attendees viewed the webinar on their own.
- **Value of Information—is described in the schematic that follows.**
  - Participants place high value on the educational aspects of the webinar, both in terms of learning about the system AND what is happening in Alberta.
  - Participant written comments echo the value of the webinars—both for personal learning and for giving profile to the issues and opportunities.



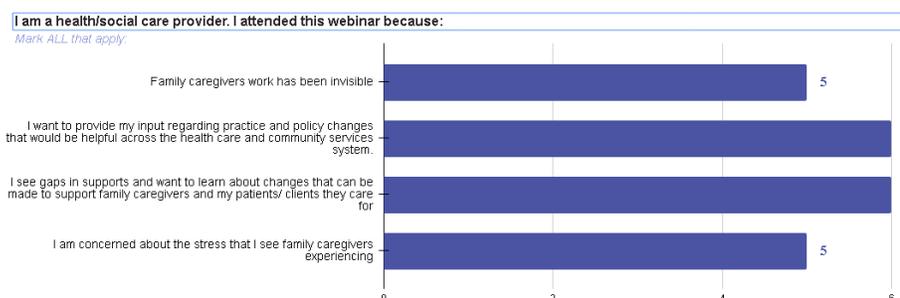
#### 3.2 Motivation for Attending this Webinar

- Developing momentum for change from the perspectives of what people want to see for their futures is an important driver for systemic change.
- The post-webinar survey asked for feedback from three perspectives—with clarity by all parties regarding the need for change.

##### 1. From the Family Caregiver: Outlines the strong desire to see/be part of change.

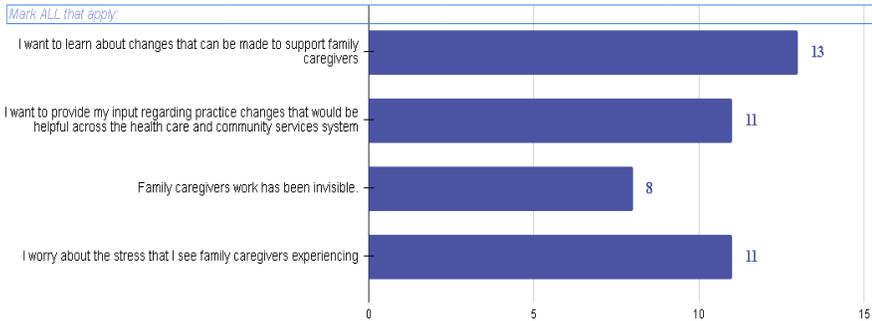


##### 2. From a Health/social care provider: Reinforces the need and desire for change.



### 3. From an Educator or Citizen Interested in Change: Continue the need and momentum for change

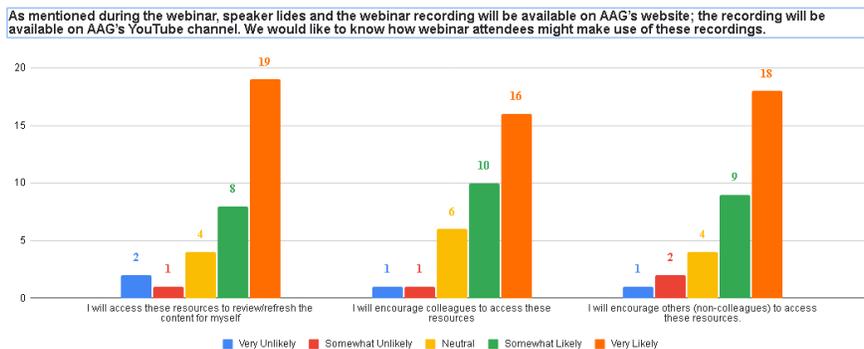
I am an educator or citizen very interested in Alberta's transformation journey to improve quality of living for older adults. I attended this webinar because:



- Respondents provide grass roots feedback from persons directly impacted, health & social care providers & citizens/policy advocates. Input indicates three factors important to moving forward:
  - recognition of “current pains” re caregiver stress and invisibility of caregiver work.
  - desire to learn about opportunities for change.
  - motivation to be involved and contribute to change.

#### 3.3 Expanding Capacity /Networks for Change

Respondents clearly see value in accessing speaker slides & video recordings. The intent to share these materials was significantly higher than in previous webinars. Chat comments indicate the desire to access speaker slides as soon as possible (they are placed on AAG’s web within 1 week).



#### 3.4 Summary: Value of Webinar for Learning & Engagement (Aim 1 for the webinar series)

- Attendees valued the opportunity to learn from speakers, with their very relevant content. There is broad reach and momentum to move forward.
- The importance of this topic was underscored by participant comments re webinar value and the high indication of intent to share materials from the Webinar with colleagues.
  - ....Thank you to the organizers and panelists. Amazing work. The evidence helps advocates and caregivers to raise awareness and influence policy.
  - ....Great presentations. So informative and very reflective of the caregiver experience. Thank you so much.

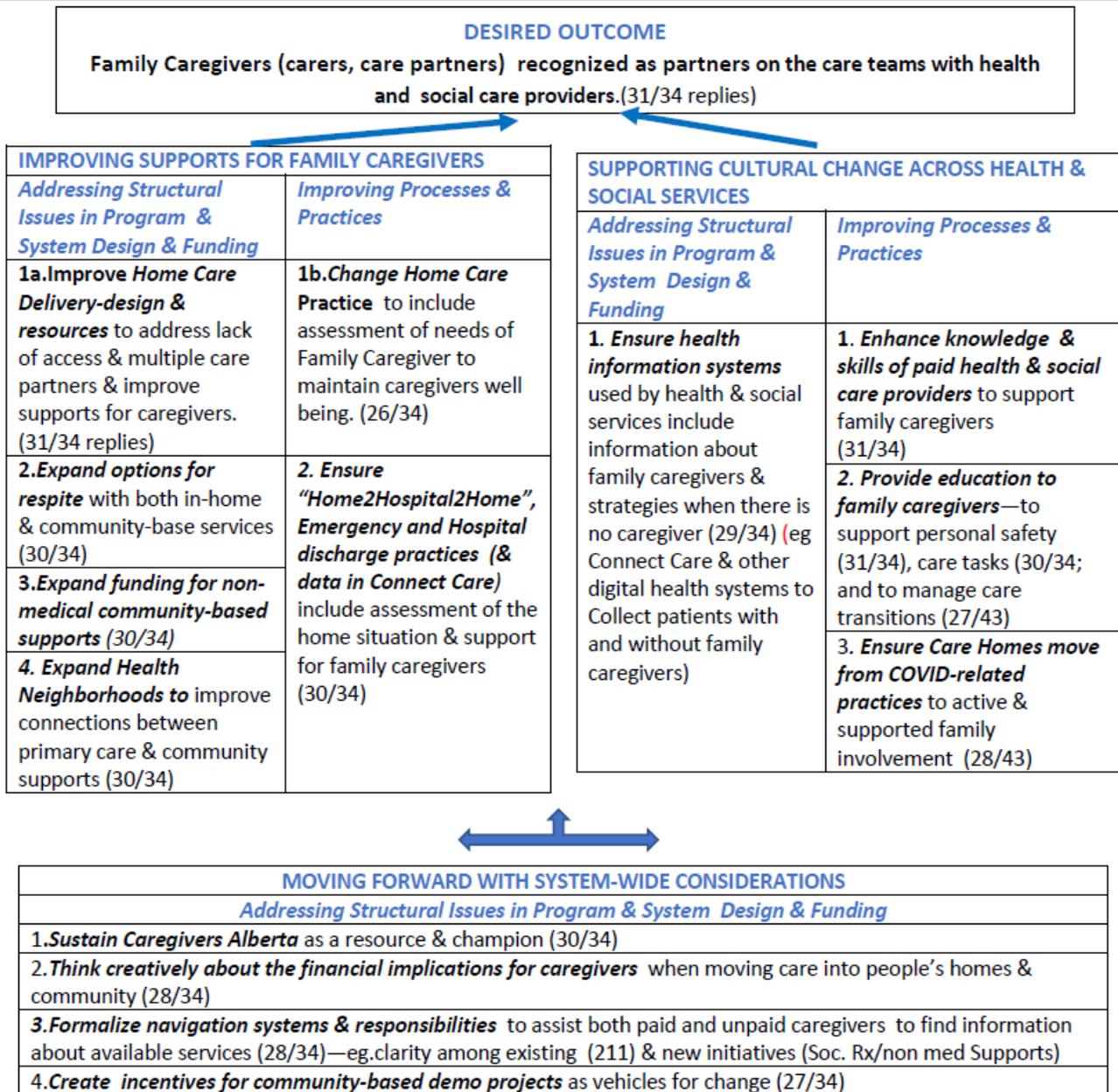
## 4.0 WHAT MATTERS TO PARTICIPANTS

### 4.1 Participant Comments, from Q & A content, create context for the next section re priorities for change. Of note, the energy of participants to contribute came through with one of the highest levels of input to the Q & A box across webinars to date!

- **Participants gave practical examples of how we need to think about caregiving.**
  - ...There is a common tendency to talk about “caregiving” or caregivers as a homogenous group. Yet there are many variations. In many communities, adult children are compelled to take leaves of absence from their own work/studies.*
  
- **Participants described service concerns.**
  - ...Experience disconnects between Home Care focus on service provision for the care recipient and suggestions from Caregivers Alberta.*
  - ...Very much agree in the community-based approach but how do we get support? Has been difficult to go to our local community association to support us. Is there a model we might use, even to establish the need? We know we have 1200 seniors in our community but have only contract with approximately 70.*
  - ...Need to watch for unintended consequences with innovation strategies—downloading of care expectations on family without concurrent planning for support; expecting new technologies to enable carers when their ability to use this technology is low and this new expectation becomes more stress.*
  - ...Can you provide a map to different supports and where a caregiver can become more knowledgeable and educated to his/her care for the dependent person (a social worker’s perspective).*
  - ...Can Caregivers Alberta provide bridging funding? NO— Nova Scotia has a program to address caregivers financial needs.*
  - ...How can the new models of Home Care (self-managed care; invoicing program) address financial concerns for caregivers?*
  
- **Finally, comments provided perspectives re the need to rethink how we value formal and informal care**
  - \*\*Great insight about the need to for recognizing the essential supplemental nature of “formal” caregiving and caregivers. Caregiving is not a set of informal supports!*
  - ...Even if in policy terms if we are starting to recognize the value of “integrated” care, both formal medical and health education and non-formal education/awareness raising are lagging seriously in terms of addressing the critical need to transform the system.*
  - ...What is stopping Canada from implementing a guaranteed basic income for caregivers?*
  - ...When any care recipient is “sent home”, what is stopping us from sending the necessary supports with the care recipient to be received by the family caregivers?*
  - ...Where are costs of the beds provided by family caregivers—in the family home accounted for that would otherwise be accounted for in an institution?*
  - ...Even though economy is the focus of this discussion, one must not lose sight of the fact that this is one of the multiple dimensions of sustainable health, both for people and for a dynamic system.*

## 4.2 Priorities for Action

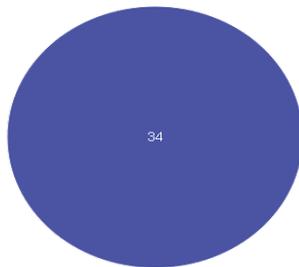
- **Survey respondents placed a check mark in the box that best described their view of the priority for each of the change topics being discussed in Alberta and ranked their priorities for action and opportunities for change. Rankings for all questions were skewed to Very important and Urgent and Very Important.**
- **As a guide to action, participant priorities are depicted in the following schematic (# of responses combine numbers of replies ranked Very important & Urgent; Very Important). The schematic illustrates the importance of systemic change (the structural components) to create an environment that will support paid and unpaid workers to support family caregivers with sustainability for the future.**



### 4.3 Summary Reflection—What Matters to Participants (Aim 2 for the webinar series)

- As a summary question, survey respondents were asked the following question, with **100% support for a future with a Family Caregivers Strategy to unify initiatives across the province.**

Does Alberta need a Family Caregivers Strategy to support the vision of a province with a priority on healthy aging and quality of life for older Albertans?



● YES—it would unify initiatives across government ministries and commur

- The schematic in section 4.2 provides a beginning framework for actions within a Family Caregivers Strategy.
- Participant comments acknowledged the value of Caregivers Alberta as an important resource & champion for family caregivers.
- The full potential for an Alberta Strategy for Caregivers and Strategy Mapping is illustrated by the following summary of additional points of connection in such a strategy:
  - ***Including Family Caregivers in Current System Change Initiatives to Enhance Integrated Health and Social Care Systems/Environments for Family Caregivers:***
    - **Bill 11** (the new Continuing Care Act); how will new standards impact family caregivers?
    - **AH system transformation initiatives:** Home Care redesign, Social Prescribing /increasing non- medical supports, Home2Hospital2Home, Modernizing Alberta’s Primary Care system, Acute Care Bundles.
    - **Healthy Aging Alberta’s** work to unify the community-based sector and integrate thinking and practices at the community level regarding social determinants of health (**their Healthy Aging Principles**).
  - ***Mobilizing spread of the work of the Caregiver-Centered Care Health Workforce Education co- design team*** led by Dr. Jasneet Parmar, Professor Department of Family Medicine, University of Alberta [www.caregivercare.ca](http://www.caregivercare.ca), with 3 Levels of Education: Foundational, COVID19, Advanced Training for health providers to support family caregivers: Recognize, Communicate, Partner, Foster Resilience, Navigate, Change culture and context of care.
  - ***Linking with other programs that provide caregiver skills training*** e.g, Norquest College <https://www.norquest.ca/programs-and-courses/programs/family-caregiver-wellness-workshops/>, Alberta Caregiver College <https://caregivercollege.ca/> and McMaster University Caregiving Essentials and Family Engagement in Research Free online, micro credentials : Enhance your knowledge and confidence in your caregiver role.

- **Linking with other work across the province to improve support for family caregivers**, including:
  - **Strategy mapping by the Dementia Network in Calgary** and their work to understand and plan supports for persons impacted by dementia
  - Family Caregiver Centre Calgary Zone  
<https://www.albertahealthservices.ca/services/Page13155.aspx>
  - **Improve Navigation 211**, Caregivers Alberta, SAGE Seniors, Kerby Centre, Helpseeker/<https://helpseeker.org/navigi/>
- **Including the need to improve identification of caregivers in digital health information systems**: Connect Care, Meditech, Primary Care, with records of who has and does not have caregiver to understand differences in unmet needs, health and social care use.
- **Linking with National initiatives**, such as Statistics Canada, Canadian Centre for Caregiving Excellence, and learning from such experiences as US The Caregiver Advise, Record, Enable (CARE) Act-Preparing caregivers for patient's discharge home. Ask patient if they have caregiver, Notify caregiver of planned discharge date, Provide care skills training needed on discharge. <https://www.aarp.org/ppi/info-2017/from-home-alone-to-the-care-act.html>
- **Providing support for this strategy is the call to action** sounded by the Canadian Institutes of Healthcare Information with their data that 1/ 9 people newly admitted to LTC have same needs as those still at home. <https://www.cihi.ca/en/> and that 1-in-9-new-long-term-care-residents-potentially-could-have-been-cared-for-at-home. They reported concerns much like participants in this webinar.
  - **Difficulty navigating the health care system** — People experienced confusion and challenges around who to contact, what services were available, the amount of time required to coordinate services and the lack of continuity across the system.
  - **Financial barriers** — Because publicly funded home care does not cover all costs associated with caring for someone at home, some families experienced significant out-of-pocket expenses. Those living in rural and remote communities faced higher travel costs for medical appointments and limited availability of home care services and supports.
  - **Responsiveness** — People emphasized the importance of reliable home care staff, as well as the need for services that were flexible to the changing needs of the person receiving care.
  - **Access to special services** — People highlighted the need for social and emotional support, help with non-medical needs and services tailored to their language and cultural needs.

## 5.0 Summary Observations: Webinar 6 Underscores importance and Opportunities for Valuing Care and Family caregivers

*Alberta's opportunity for change (MNP report) relies heavily on a range of changes with family caregivers essential support for change and success with each of the policy layers.*

**ALBERTA'S OPPORTUNITY: VISION** *Albertans are supported to be healthy and active in their community, with an improved quality of life, and they are engaged, empowered, and enabled to live in inclusive communities with social connectedness and healthcare access.*

Populations Characteristics	Example Features and Supports	Policies
<p>1 "Healthy" individuals with Minimal Care Needs</p>	<ul style="list-style-type: none"> <li>Self Management with Digital Assistance/Information</li> <li>Healthy Living Habits</li> <li>Senior Support Services</li> <li>Government Address Social Determinants of Health</li> <li>Insurance Programs</li> <li>Primary Health Care</li> </ul>	<p>Population-based Health Policies</p>
<p>2 Individuals with Moderate To Complex Care Needs</p>	<p>Home Care, Community Care, Personalized Living, In-Home and Residential Care, Self-Directed Care, "Your Home"</p>	<p>Complete Care Provided at Home and in the Community</p>
<p>3 Individuals with Highest Care Needs</p>	<p>Residential Support Services, Long Term Care</p>	<p>Continuing Care Services Provided in RBC</p>

**93% of older adults live in the community; the goal is to shift to increasing support for living in Tiers 1 & 2.**

**7% live in continuing care settings**

**1 in 4 Albertans provide unpaid care to persons across the age span AND across setting where Albertans live and work.**

**Family caregivers are diverse: primary groups are women, lower income individuals & baby boomers. Lack of support can create negative health impact for carers.**

**"Informal Caring" is valued at 33% of the Alberta Health Care budget in Alberta (2021); informal caring is critical to sustainable service delivery .**

**Speakers challenged all stakeholders with this statement: the care economy (paid and unpaid) is the new policy priority for today and tomorrow, given demographic trends, changing public expectations and need for sustainability of health and social systems.**

- Strategies to address seniors' services workforce have been the focus of AAG' recent Workforce Think Tank.
- This webinar is a **call for action to formalize a Caregiver Strategy** with a vision for valuing family caregiving and exemplifying this with intentional and integrated supports that enable these carers to sustain care and maintain their own wellbeing—and that improve ease of paid caregivers to be contributors across health and social services. ***We need the wrap-around framework to underpin Alberta's transformation goals and strategies "the hatched box around the MNP tiers for policy change"***.
- An Alberta Caregiver Strategy and Strategy Mapping to Support Alberta's Family Caregivers would provide an integrated workplan to connect/ integrate health and community care systems, who is responsible for what strategies, and practical research, evaluation, tracking of output, and outcomes to understand if programs are effective & how they might be improved.

AAG looks forward to supporting next steps where possible and monitoring action taken.

AAG's upcoming initiatives offer opportunities to contribute to this future:

1. *Webinar 8: Innovation in Community-based Housing*—Innovation in Communities and Housing for Health and Wellbeing (March 15) --with the importance of intentional design for social connectedness and integration of community supports.
2. *AAG/Healthy Aging Collaborations* regarding potential for cross-sector application of HAA's Principles for Healthy Aging which are based on social determinants of health—key to thinking holistically about family carers and supports for living well in community





