

Innovating Integrated Supports for Alberta's Family Caregivers Strategy & Action Plan

Discovery Report: What We Heard & Proposed Priorities

September 2024

Introduction

Over the summer, the **Innovating Integrated Supports for Alberta's Family Caregivers** project team interviewed 44 individuals (see Appendix A) involved in the providing health and social/ community programs and services to Albertans as part of Phase 1 of the project (see below). Our goal was to gain insights into the current efforts underway to support family caregivers and the challenges and successes in this work. Participants also shared their hopes and advice for the strategy work. These conversations suggested several initial areas of priority or focus for the strategy for us to consider.



Project phases and timeline for Innovating Integrated Supports for Alberta's Family Caregivers Strategy & Action Plan.

Current Efforts to Support Family Caregivers in Alberta

Services:

- Navigation—information, knowledge, access
- Social prescribing
- Home care, Client-directed Homecare
- Intake, assessments and referrals
- Non-medical supports
- Specialized support teams

Programs:

- Support group, peer support
- One-on-one coaching
- Grief and loss support
- Early intervention programs
- Respite
- Adult day programs
- Recreational programs
- Social programs

Information:

- Hubs, centres, single points of contact
- Information channels, platforms, guides
- Mapping (services, connections)
- Database of resources

Capacity Building

- Education, training for providers
- Education for family caregivers
- Research, studies, white papers
- Advocacy, public policy and awareness
- Prevention efforts

Engagement

- Family caregiver consultation, engagement in planning
- Designated support partners; patient partners
- Community engagement
- Outreach
- Volunteerism

Development

- Community-led initiatives
- Distribution of funding and grants
- Evaluation and measurement
- Innovation models, pilots and projects
- Program development

Collaboration

- Collective planning and priority setting
- Co-ordination of efforts and resources

Challenges and Barriers

Participants identified the challenges and barriers impacting their ability to support family caregivers and the challenges family caregivers encounter, often drawing on their own experiences as family caregivers. Comments ranged from system challenges to the daily realities both providers and family caregivers face.

Unsustainable system reliance on caregivers; burnout.	System silos, illness focus, reactive, cost driven	Insufficient staffing, funding, resources hinder effective support for caregivers.	Complexity of navigation: process, access, information.	Require clarity on accountability to involve/support family caregivers
Crisis-driven response; stress of changes, transitions	Limited programs and access: appropriateness, availability, rules	Financial strain and costs of caregiving on caregivers	Fragmented data collection and access to data on caregivers	Lack of recognition and support for working caregivers

Some Successes and Progress

Those we interviewed shared some of their success stories. The interviews provided insight into some areas of investment and progress in supporting family caregivers in Alberta that the strategy might build on—including examples of better co-ordination and teamwork, education and awareness, new programs and services and creative problem-solving approaches. Here's a look at some of the areas of focused effort, success and points of progress that were shared by the participants.



Hopes

Participants shared hopes for what a successful strategy might achieve:

- Caregivers feel more connection
- Caregivers feel more supported and have supports they can rely on
- People can find resources easily
- People needing care have dignity + agency
- People can age in right place
- No one feels like a burden
- Everyone has the ability to thrive
- Health system values care as much as cure

Advice

They also shared advice for developing and implementing the strategy:

- Focus on support for person, caregiver and community
- Focus on building relationships, engagement and trust
- Ensure partner commitment + continuity
- Ensure clear roles and expectations
- Have a flexible action plan
- Make it practical and actionable.
- Don't duplicate or reinvent.
- Build on what's worked.
- Be nimble, adaptive and responsive; use rapid PDSA cycles .

Potential Priority Areas

The following options for priorities to address in the **Innovating Integrated Support for Alberta's Family Caregivers** Strategy & Action Plan emerged from the interviews for further discussion and input. These are not presented in any order of priority.

A	B	M
Identify caregivers in health and social/community care service provision and policy.	Identify family caregivers' needs and risks early in the care trajectory and provide timely access to supports and services.	Address the gap in practical supports to enhance family caregiver quality of life and wellbeing
Recognize and integrate family caregivers as essential partners in the care team.	Engage family caregivers in conversations about their needs to provide care and maintain their wellbeing.	Strengthen mental health supports for family caregivers.
Incorporate caregivers in care planning and pathways , ensuring they are recognized, consulted and their role is defined.	Enhance access to flexible services , such as respite care and day programs, to meet diverse family caregiver and care recipient needs, offering family caregivers choice and control through supportive policies and practices.	Expand workplace supports for employed family caregivers.
Document caregiver involvement in patient and caregiver records; enhance data collection for care co-ordination and evaluation/research (Connect Care)	Ensure facilitation in navigation with processes for warm hand-offs, integrating care co-ordination at point of care with a clear provider responsibility.	Design culturally safe care models that respect family caregivers' diversity, ensuring equity, diversity and inclusion as core principles.
Clarify privacy and consent processes to support active caregiver involvement	Enhance continuity of care and communication among providers to reduce challenges in navigation and co-ordination. Ensure referral outcomes are communicated to both the referring provider and the family caregiver.	Reduce the financial burden of family caregiving through targeted financial supports.
Train health and social/community care providers on best practices for including caregivers and ensure resources to include caregivers are available.	Integrate health and social/community services to streamline co-ordination for family caregivers and care providers	Develop a robust research and evaluation framework to measure the impact of family caregiver support initiatives

Appendix A:

Participants Interviewed July - September 2024

Ambere Porter, Alzheimer Society of Alberta and NWT

Arlene Huhn, Alzheimer Society of Alberta and NWT

Barb Ferguson, Dementia Network Calgary

Blair Wold, Connecting People and Communities for Living Well

Brian Schmidt, Alberta Health Services

Carla Moore, Leduc Beaumont Primary Care Network

Cathy Ault, Age Friendly Cold Lake

Darrel Gregory, Caregivers Alberta

Debra Samek, Alberta Health Services

Dr. Carole Estabrooks, University of Alberta

Dr. Haidong Liang, West Edmonton Seniors Activity Centre

Dr. Jacqueline Pei Otter, University of Alberta

Dr. Jennifer Stickney Lee, St. Albert

Dr. Jim Silvius, Alberta Health Services

Dr. Karen Chan, Edmonton

Dr. Michelle Grinman, Calgary

Dr. Richard Lewanczuk, Alberta Health Services

Dr. Sheny Khera, Edmonton

Dr. Trevor Byers, Leduc

Dr. Vivian Ewa, Alberta Health Services

Elaine Finseth, Alberta Health Services

Gail Burns, Edmonton O-day'min Primary Care Network

Helen Lightfoot, Connecting People and Communities for Living Well

Holly Mattias, University of Alberta

Isabel Henderson, Alberta Health Services

Jennifer Olson, Covenant Health

Jennifer Salt, Alberta Health Services

Jocelyn Cuthbert Mora, carya

Johnna Lowther, Caregivers Alberta

Judy Birdsell, Imagine Citizens Network

Karen McDonald, Seniors Association of Greater Edmonton

Kim Brundit, Alzheimer Calgary

Kym Schreiner, Edmonton Seniors Co-ordinating Council

Lesley Myles, Alberta Health Services

Lisa Stebbings, carya

Lola Fariyibi, Unison at Kerby Centre

Megan Hincks, carya

Natalie Joly, ElderCare Edmonton

Rhonda Romolock, Huntington's Society of Canada Edmonton Chapter

Sabrina Ball, Alberta Health Services

Sarah Allen, Unison at Kerby Centre

Shawna McGhan, Alberta Health Services

Sheila Hallett, Edmonton Seniors Co-ordinating Council

Stephanie Banszky, Healthy Aging Alberta