Collaborative Research Grant Initiative: Mental Wellness in Seniors and Persons with Disabilities

Ideas Fund Final Report

March 2013 – Anna Mann
EXECUTIVE SUMMARY
Caring for a family member or friend has a huge impact on the caregiver; they are more likely to have depression, be in poor physical health, and are at risk of isolation and burnout.

A common challenge family caregivers identify is that care providers “just don’t understand”. Care providers would include “system” supports such as homecare staff, occupational therapists, recreation therapists, doctors, nurses, spiritual care chaplins; those who are involved with caregivers as a result of a professional connection to the care recipient. Because our health system is patient-focused, the needs of the family caregiver get overlooked. The supports that are available for caregivers often help make them better caregivers for their loved one, rather than addressing their needs. Caregivers who connect with this agency relate being exhausted by their role. There are complex family dynamics that create emotional distress. Legal and financial burdens are difficult to deal with and the management of continuing care of the care recipient is always ongoing. Caregivers report feeling invisible and unacknowledged. One caregiver described her experience as “My name has become ‘how’s your mother.’”

The aim of the Caregiver Navigator project is to help care providers, including health professionals and community workers, understand the caregiver’s experience. Navigators learn how they can help caregivers stay healthy by providing understanding, support and access to the resources they require for both themselves and the care recipient.

The Alberta Caregivers Association developed a one-day training program and manual for care providers, and offered two training sessions as a part of the project.

The results of this project reflect the need for this type of education for care providers throughout the health and social service systems. After participating in the program, participants said that they had a better understanding of where caregivers were coming from, were more empathetic and took more time to listen to caregivers, and felt more comfortable offering support. They also found the training manual to be very helpful and many program participants said they had shared it with their coworkers.

RESEARCH OVERVIEW
Objective(s)
The objective of the Caregiver Navigator project is to support family caregivers by increasing the capacity of health professionals and community agency staff to:
1. Identify caregivers early in their caregiving journey
2. Identify and assess caregivers’ needs
3. Support caregivers to adopt preventative, self care practices
4. Facilitate access to resources and referrals

Background
It is estimated that 1 in 4 Albertans provide unpaid care and coordinate health services for a family member/friend living with illness, disability or challenges due to aging. Their contributions to our society can no longer be taken lightly. While there is a growing recognition of the “work” of caregiving, there are still very few program supports and services that focus on the wellbeing of the caregiver.

Many caregiver support programs instruct the caregiver on “how to” better care for their care recipient. The recipient is someone who lives with challenges due to disability, illness or age. Often, these types of programs provide information on disease progression, aids to daily living availability and how to perform basic medical procedures at home. Although helpful, these types of supports fail to
acknowledge the negative social, financial and health impacts on the family caregiver who provides day to day, night to night, week in and week out care.

Caregiving has a number of negative impacts on the caregiver:
- Caregivers frequently report feelings of grief, guilt, anger and resentment.
- A significant number (40-70%) have the symptoms or a diagnosis of major depression.
- 17% fit a high stress profile and are at risk of burnout.
- More than 30% report missing out on social activities, which contributes to isolation.
- 33% of callers to the Alberta Caregivers Association (ACGA) in 2012 described feeling exhausted.

The concept of an education program for professionals in the ‘system’ on how they can better work with and support caregivers has been identified as a preventative strategy by the ACGA and various stakeholders for years. Members of the Caregiver Support Team, a collaboration of over 30 Edmonton-area social service agencies, government services, Primary Care Network (PCNs) and private providers, meets monthly for the purposes of networking, sharing expertise, expediting the referral process, identifying gaps in services and to develop strategies that will build and strengthen enhanced caregiver support services. The consensus among members is that greater understanding and support for caregivers is required – across all health and social service systems.

With advances in medical care allowing people to live longer and the aging population, the reliance of our health and social service systems on family caregivers will continue to grow. This can already be seen in the move towards ‘community-based care’. In order for our system to continue functioning, more attention needs to be paid to the well-being of the family caregivers or else we will see an increasing number of family members and friends succumbing to burnout.

The majority of caregivers do not self-identify until they are well entrenched in their caregiving role. As a result, most caregivers don’t even think to seek help until they have reached a crisis point. Because of this, it has been very difficult for the Alberta Caregivers Association to promote self-care as a preventative approach. The Caregiver Navigator concept proposes that by having care providers throughout the system who are responsive to caregivers, this will allow caregivers will receive support earlier and be less likely to burn out.

**Approach and Methods**

The Caregiver Navigator project involved the development of a one day workshop and program manual for health professionals, service providers and community agency staff. A committee consisting of two registered nurses, a professor in the faculty of nursing from the University of Alberta, three social workers and two agency staff was recruited to refine the concept and develop the content. To begin, a literature scan was conducted to examine caregiver experience and need using the following key words: general caregiving; benefits of caregiving; family dynamics; spirituality; system navigation; caregiving assessments; communications; caregiver grief, loss and hope; caregivers and end of life; caregiving and employment.

From the information gathered, the workshop was developed in five sections:

1. **Understanding caregiver burden:** For the purpose of this project “caregiver burden” was defined as the culmination of all the tasks and responsibilities that caregivers fulfill in their caregiving role. In contrast, “caregiver strain” is the caregiver’s perception and response to how difficult their role is. Some caregivers with relatively light burden (few responsibilities) may have very high strain because they don’t have adequate coping mechanisms, resilience skills or other person to assist in caring.

Research on the most common domains of caregiving presented participants with a big picture, practical overview of the daily stresses caregivers face. Included were challenges related to:
Health and Wellness, Employment, Finance, Legal, Housing and Transportation, Communications, Respite, and Navigating the System.

This component of the program also incorporated a section on the intersection of culture and caregiving, and discussed the positive aspects of providing care.

2. Understanding the emotional journey: Participants were provided with a broad understanding of the complex emotions associated with the journey of caregiving and were given some insight into how to support a caregiver struggling with these emotions. Topics discussed included: Emotional Stressors, Guilt, Grief/Sadness, Anger & Resentment, Isolation, Family Dynamics, Caregiver Burnout, and Elder Abuse.

3. Identify and assess caregivers’ needs: This section discussed the role of assessments in working with and supporting caregivers. Elements of a successful assessment, considerations when selecting an assessment method, and a list of some of the most commonly used assessment tools were provided. In collaboration with Dr. Penny MacCourt and the BC Psychogeriatric Association, participants were provided with an overview of www.caregivertoolkit.ca. The Caregiver Toolkit contains two resources: the Service Providers’ Resource Guide and the Caregiver Policy Lens.

The section also discussed the value of “discussion starters” and “check-in questions” as practical tools that can be used for informal assessments and as a way to initiate discussions with family caregivers.

4. Support caregivers to develop self-care attitudes and practices: This section reviewed self-care attitudes and practices and how a Caregiver Navigator can support caregivers to adopt self-care. The components of self-care discussed included: Hope, Resiliency, Spirituality, The Physical Body, and Social Activities

Along with these components, participants were provided with a list of barriers caregivers often present to accepting help and practicing self-care.

5. Planning ahead and connecting to resources: This final component of program discussed supportive interactions and having conversations about planning ahead and the challenges of post-caregiving. A 43 page resource directory was also included. The resources for this section were compiled from the Alberta Health Services Respite Demonstration project work, The Support Network (211) and day program information.

The Caregiver Navigator program was delivered in two pilot sessions in January 2013 to a total of 17 participants. The attendees included a long term care social worker, home care employees, a PCN clinical coordinator, recreation therapists, spiritual care coordinators, disease specific agency staff, staff from the brain injury service community and a hospital rehabilitation professional.

Participants completed two evaluations as part of the project: a questionnaire (see Appendix) immediately following the program and a telephone interview 6-8 weeks after the program.

Key Findings
A number of themes emerged in the questionnaire responses and during follow up interviews. These included:

- Care providers feel they need more resources in order to support caregivers.
- Eighty-eight percent of the attendees indicated that they had regular contact with caregivers.
- Developing skills and abilities to provide appropriate supports was a key reason for attending.
- Some participants commented that while their positions existed to serve the care recipient, they spent the majority of their time working with the families.
Another theme that emerged was the value of having their experiences working with caregivers validated. Some participants discussed the sense that they had had to improvise when supporting caregivers because they weren’t sure how to respond. One participant commented that afterwards they felt “refreshed and refocused” when working in their practice.

The need for more resources could also be seen in the sharing of learning with co-workers. In particular, many said that they had shared their program manual with colleagues and identified it as an invaluable tool. Three participants also mentioned that they felt that this type of training would be valuable to all their co-workers, and there has been some discussions about providing training to the individual agencies.

- The Caregiver Navigator Training gave participants a better understanding of the scope and challenges of caregiving.

In initial evaluations and during follow-up, all participants commented that the training had broadened their view of the scope and impact of caregiving beyond their professional practice. Participants commented that they were now noticing the prevalence of caregivers and that they could see the impact caregivers have on ‘everything’. One participant described it as “nothing surprised me, but I understand it differently.”

“I have always been aware of how important caregivers are within my practice, but this has made me aware of new areas to address and make connections with those caregivers.”

Along with increased recognition of the scope of caregiving, participants said they had a better understanding of the individual caregiver, rather than looking at the ‘issue or disease’. As a result, they indicated that they were more empathetic and felt more comfortable entering into discussions.

“I used to often frame caregivers as mad, sad or bad. It has been very helpful learning that there is more behind the behaviours.”

- Caregiver Navigator participants made changes in their practice to better support caregivers

In the initial evaluation, all participants agreed that, as a result of the training, they would be able to respond more effectively to caregivers in their practice and were able to identify what they thought they would do differently. In follow-up interviews, participants identified ways their practice had changed. Generally, the program participants did not report spending more time with the caregivers (a concern identified in the questionnaire); rather they used time when they were already together differently.

Changes participants identified were:

1. More empathy/understanding when working with caregivers: participants said they now took more time to listen to caregivers and made an effort to be more empathetic. They described validating caregivers’ experiences, being more sensitive to the well-being of the caregiver, and taking time to introduce them to new information (recognizing that they may be grieving and unready for it).

2. Using open-ended questions and assessments to build rapport: participants identified asking questions as a way to engage the caregiver and signal their understanding of the challenges the caregiver might be facing.

3. More comfortable having difficult conversations: a number of participants said that they had previously avoided having conversations with caregivers because they weren’t certain how to respond or didn’t know how to follow-up. As a result of training, participants said they were more comfortable opening conversations and were not ‘afraid’ of dealing with caregivers who are angry or upset.

4. Helping caregivers identify strategies to cope: Navigator participants discussed helping caregivers explore and problem solve, supporting caregivers to find solutions that met their needs and encouraging them to find self-care practices that fit with their lifestyle.

“This workshop has definitely helped me to move forward. I will continue to expand on my skills to identify the barriers that prevent caregivers from practicing self-care.”

5. Sharing resources and making referrals: participants reported handing out resources like the ACGA’s Bill of Rights and making referrals to other government and community programs.
• **Navigator Training had personal relevance to participants**
  Almost half of the participants indicated that they were caregivers in their personal lives. Many said the training helped them process their own experiences. Some also discussed the similarities and differences between caring in their professional and personal lives. Recognition of compassion fatigue and the importance of self-care on the professional level were also noted.

**Conclusions**
Care providers are generally aware of caregivers and recognize that the caregiver role can be challenging; however, they are unsure how to address the caregiver’s needs, and how to balance providing care for the client/patient with supporting the caregiver. Training and resources can help care providers identify ways in which they can be supportive. While measuring the impact Caregiver Navigator training had on caregivers who interacted with project participants was outside the scope of this project, participating care providers felt that they were better able understand and respond to caregivers’ needs. Given that caregivers often identify lack of understanding from health professionals as a challenge, these results suggest that education for care providers may help alleviate some of the stresses caregivers experience and help prevent burnout.

**Implications for Policy or Practice**
*‘Patient-centered’ should expand to include the dyad of patient and caregiver.*
The interest in Navigator Training and the number of participants who said they subsequently shared their learning and the program with colleagues, suggests that while they are not officially part of the care system, there is a need to support caregivers. While participants said that they now were more understanding and empathetic of caregivers, they did not feel they had much time to focus on the caregiver in their practice. Rather, they discussed how they had incorporated their learning into existing practices.

*Care providers need education around the role of, and challenges facing, caregivers.*
Participants identified a lack of knowledge around how to support caregivers as the primary reason for attending. A number said that in their practice they dealt primarily with the caregivers of their clients and that they felt ill-equipped to do so. Education about caregivers could be included in the curriculum of professional training programs or as a professional development opportunity for care providers.

**Directions for Further Research**
While Navigator participants reported that they made changes to their practice in order to better respond to the needs of caregivers, measuring the impact of these changes on the caregiver was out of the scope of this project. Further research is needed to determine if caregivers who are supported by Caregiver Navigators have better outcomes. The feasibility of having care providers dedicated to supporting caregivers could also be examined.

**Knowledge Dissemination and Translation Activities**
The Alberta Caregivers Association will be presenting the results to its membership, mailing lists and stakeholders. The ACGA has applied to present the project at the Grey Matters Conference in September, and has discussed the possibility of offering the program as a training course prior to a national case management conference in 2014. We have received interest in the Caregiver Navigator project from a wide range of community and health agencies including long term care, senior’s centres, immigrant serving agencies, community health nurses, home care workers and hospital workers as well. We will also work with contacts in health programs to encourage the incorporation of caregivers into the curriculum.

A copy of this research project will be sent to all stakeholders involved with this initiative for discussion and follow-up.
The ACGA will also include the Caregiver Navigator program into a project it is now involved in with the Ministry of Health to increase Albertan communities’ capacity to support caregivers.

**Principal Applicant (Team Leader)**

<table>
<thead>
<tr>
<th>Name</th>
<th>Position Title, ACGA</th>
<th>Topics of interest</th>
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<tbody>
<tr>
<td>Anna Mann</td>
<td>Executive Director</td>
<td>Caregivers</td>
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**Project Partners (Team Members)**

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<thead>
<tr>
<th>Name</th>
<th>Position Title, ACGA</th>
<th>Role</th>
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<tbody>
<tr>
<td>Bonnie Hoffmann</td>
<td>Associate Director, ACGA</td>
<td>Project developer, researcher, contributor, facilitator</td>
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<tr>
<td>Rachelle Gietz, RSW</td>
<td>Caregiver Advisor, ACGA</td>
<td>Contributor, facilitator</td>
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<tr>
<td>Debbie Cameron-Laninga</td>
<td>Program Coordinator, ACGA</td>
<td>Contributor, format</td>
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<tr>
<td>Debra Paches, BScN, RN, GNC(c)</td>
<td>Older Adult Rehabilitation (OAR) Team</td>
<td>Contributor</td>
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<tr>
<td>Wendy Duggleby, PhD, RN, AOCN, Professor</td>
<td>Nursing Research Chair Aging and Quality of Life</td>
<td>Contributor, advisor</td>
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<tr>
<td>Brittany Faux, BA, BSW, MSc</td>
<td>Registered Social Worker</td>
<td>Research and Reference</td>
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<tr>
<td>Pauline Atwood, RN, MSc</td>
<td>Director at Large, Alberta Caregivers Association</td>
<td>Contributor</td>
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<tr>
<td>Dr. Penny MacCourt, MSW, Ph.D.</td>
<td>President, B.C Psychogeriatric Association</td>
<td>Contributor, assessment tools, caregivertoolkit.ca</td>
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<tr>
<td>Darcia Arndt</td>
<td>ACGA Volunteer</td>
<td>Resource compilation</td>
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**Publications and Presentations**


Two deliveries of pilot program, January 2013
ABOUT THE ALBERTA ADDICTION AND MENTAL HEALTH RESEARCH PARTNERSHIP PROGRAM

The Alberta Addiction and Mental Health Research Partnership Program is comprised of a broad-based multi-sectoral group, representing service providers, academic researchers, policy-makers and consumer groups, working together to improve the coordination and implementation of practice-based addiction and mental health research in Alberta.

The mission of the Research Partnership Program is to improve addiction and mental health outcomes for Albertans along identified research priority themes, by generating evidence and expediting its transfer into addiction and mental health promotion, prevention of mental illness, and innovative service delivery.

The Research Partnership Program sets out to increase Alberta’s excellence and output of addiction and mental health research findings, and to better translate of these findings into practice improvements.
# APPENDIX

## Caregiver Navigator Pilot: Evaluation

<table>
<thead>
<tr>
<th>Date:</th>
<th>Location:</th>
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I am attending this workshop because:

- I work with caregivers in my professional practice □
- I am a current/past caregiver □
- Other (please explain): □

### Understanding the Caregiver Experience and the Emotional Journey

<table>
<thead>
<tr>
<th>Statement</th>
<th>Disagree</th>
<th>Somewhat Disagree</th>
<th>Somewhat Agree</th>
<th>Agree</th>
<th>Not Applicable</th>
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<tbody>
<tr>
<td>Because of this workshop, I have a better understanding of the challenges caregivers face</td>
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<td>I have a better understanding of why caregivers experience difficult emotions like anger and grief</td>
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<td>I understand the difference between caregiver burnout and elder abuse</td>
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<td>This workshop has changed the way I view caregivers in my practice</td>
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Please explain how your view of caregivers has changed or why it has not:

### Identifying and Assessing Caregiver Needs

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<tr>
<th>Statement</th>
<th>Disagree</th>
<th>Somewhat Disagree</th>
<th>Somewhat Agree</th>
<th>Agree</th>
<th>Not Applicable</th>
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<tbody>
<tr>
<td>I understand how I assess caregivers’ needs using informal ‘check-in’ questions</td>
<td></td>
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<td>I have tools I can use to assess caregivers’ needs</td>
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Alberta Addiction and Mental Health Research Partnership Program
Do you think you will use assessments (formal or informal) in your practice? How will you use them?

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<thead>
<tr>
<th>Self-Care Attitudes and Practices</th>
<th>Disagree</th>
<th>Somewhat Disagree</th>
<th>Somewhat Agree</th>
<th>Agree</th>
<th>Not Applicable</th>
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<tr>
<td>I can identify barriers that prevent caregivers from practicing self-care</td>
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<td>I understand what is meant by self-care</td>
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<td>I believe that it is important for caregivers to practice self-care</td>
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<td>This workshop has given me insight into how to introduce the topic of self-care with caregivers in my practice.</td>
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What is something you could say to a caregiver to encourage them to ‘take care of themselves’?

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<thead>
<tr>
<th>Planning Ahead and Connecting to Resources</th>
<th>Disagree</th>
<th>Somewhat Disagree</th>
<th>Somewhat Agree</th>
<th>Agree</th>
<th>Not Applicable</th>
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<tr>
<td>This workshop has increased my knowledge of resources available to caregivers.</td>
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<td>I will now be able to link caregivers with more resources.</td>
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<td>I believe I am better equipped to help caregivers ‘plan ahead’.</td>
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<tr>
<th>Integrating Caregiver Navigator into Practice</th>
<th>Disagree</th>
<th>Somewhat Disagree</th>
<th>Somewhat Agree</th>
<th>Agree</th>
<th>Not Applicable</th>
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<tbody>
<tr>
<td>Because of this workshop, I will be able to respond more effectively to caregivers in my practice</td>
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What, if anything, do you think you will do differently?

Did anything you learn surprise you? Please describe:

What part of this workshop was the most valuable for you?

Is there anything you think was missing? Anything that should be changed or added?

<table>
<thead>
<tr>
<th>Material/Facilitator/Environment</th>
<th>Disagree</th>
<th>Somewhat Disagree</th>
<th>Somewhat Agree</th>
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<tr>
<td>The program material is relevant to my position</td>
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<td>Amount of material was appropriate for the time allotted</td>
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<td>Learning environment was professional</td>
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<td>Facilitators responded appropriately to questions</td>
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Caregiver Navigator Pilot
Follow-Up Phone Interview Questions

1. Did the workshop change the way you interact/work with caregivers in your practice? Could you provide examples?

2. Do you think family caregivers are now more responsive to your supports? Examples?