



Caregiver Consultation 2010: Towards a Provincial Caregiver Strategy

Final Report on Alberta Caregiver Strategy Consultations

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This document contains data collected and analyses conducted using qualitative methodologies. Thus, biases of the Alberta Caregivers Association and project staff may be reflected in the results despite all efforts to remain objective during both data collection and analytic steps.

Any views or opinions inadvertently expressed in this document are solely those of the ACGA and/or the authors and not of any member of the Consultation Committee, stakeholder organizations, or consultation participants.

Further copies of this document can be obtained by calling the Alberta Caregivers Association. A copy is also on our website at www.AlbertaCaregivers.org

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Preface

The Alberta Caregivers Association (ACGA) defines a caregiver as “a family member or friend who provides care for someone living with challenges due to disability, illness, or age”. Since 2001, we have been providing information, education, support, networking, and advocacy to further our mission, namely to empower and promote the well-being of caregivers in Alberta. We pride ourselves on being *an organization of caregivers for caregivers*: we are to-date the only organization in Alberta that is exclusively geared towards protecting the well-being of caregivers. The ACGA employs a community development approach in all aspects of its work. This is evident in the use of participatory methods to understand issues relevant to caregivers and solution-oriented collaboration with stakeholders like public policy makers and professionals in addressing systemic issues.

The ACGA is leading efforts to create the first broadly based, community-driven, and comprehensive provincial caregiver strategy in Alberta. This document, the Alberta Caregiver Strategy, will highlight the issues that caregivers face every day and offer tangible solutions and supports that government, service providers and community agencies can develop and implement to better serve the needs of Alberta’s caregivers.

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Towards a Provincial Caregiver Strategy

A. Who are Caregivers?

Caregivers, those who care for a family member or friend living with challenges owing to illness, disability or old age, are an essential part of our social and health systems. According to the 2007 General Social Survey¹ conducted by Statistics Canada, 11.6% of the Canadian population over the age of 45 required care for a long-term health condition or physical limitation. Of these, only 19% received paid care only, through the formal health system. Just over 27% received unpaid care only, with the remainder receiving care from a combination of the formal and informal systems. The same survey showed that, of the population 45 years of age or older, more than 4 million individuals, or fully 1/3 provided care to another individual, with the average person providing nearly 12 hours of care per week. In Alberta, 376,000 people provide care for another individual. Including caregivers under the age of 45 would increase these figures even more. This caregiving role can be stressful, isolating, and have a negative impact on physical, mental, and financial health. And yet, caregivers are often invisible: they receive little recognition and largely insufficient support in their critical role.

Most often, caregivers are spouses, adult children, or in-laws; however, many other family relations and even friends and neighbours can become caregivers. The plight of the “sandwich generation” is well-known, if not entirely recognized: these are people (usually women) most often in their 50s who care for their children as well as elderly parents (and in-laws in some cases). They struggle to maintain these responsibilities and often lose their career goals and personal health in the process. In the meantime, children are involved in all sorts of caregiving tasks, sharing in the sacrifices of their parent(s), including family leisure time, physical and mental health, and financial hardship (National Alliance for Caregiving (USA), 2005).

Because of the anecdotally evident deficiency in respite, support, education, service coordination, and financial assistance programs available for those who care for their care recipients, many caregivers are worn down physically, mentally, financially, and emotionally to the point where they may even require care themselves. There is a general sense of urgency for raising the profile of the thousands of caregivers in our province, especially in light of current demographic trends and increasing pressures on publicly- and privately-available health and community care services.

¹ Statistics Canada. 2007 General Social Survey: Care Tables. Published July, 2009,

B. Need for a Caregiver Framework

Current caregivers provide between 80% and 90% of the care required by persons with long-term conditions, saving the formal health system billions of dollars each year. Given the changing demographics within Canada, the decreases in family size over time means that there are fewer and fewer family members available to provide care to their parents and spouses as they age. The baby boom generation are just now starting to turn 65. Coupled with increased life expectancy, the burden that is about to be placed on our health system, and more importantly, the informal care system, is immense.

In Alberta, it is timely to develop a framework which can help policy-makers, the health care delivery system, health care practitioners, and care organizations and societies to ensuring that caregivers are adequately supported and valued. We can not do without them.

C. Background to Framework Development

The consultation process to develop a provincial caregiver strategy did not start from nothing. Over the last ten years, the ACGA has been involved in and has supported efforts that have contributed to our organization's understanding of the caregiver perspective. While not exhaustive, the following are highlighted for their relevance to the Alberta Caregiver Strategy consultation process:

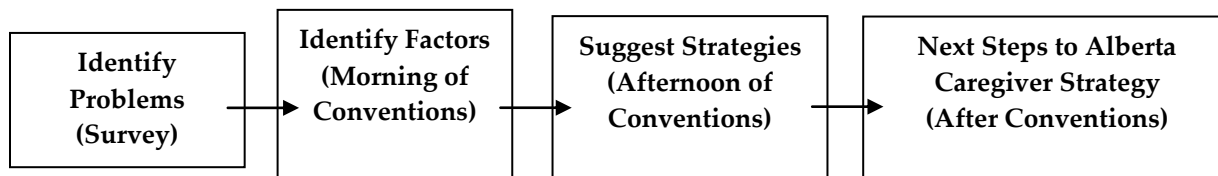
- Shining a Light on Family Caregivers' Issues, Strengths and Needs
- National Conference on Caregiving
- Alberta Disabilities Forum Caregiver Community Consultation
- Roundtables on *A Framework for a Canadian Caregiver Strategy*
- ACGA Strategic Plan 2010 – 2013

Appendix 1 - Environmental Scan, starting on page 7, provides more detail on the findings and conclusion in these reports which provided a foundation for the consultation process.

D. The Alberta Caregiver Strategy Consultation Process

As evidenced by efforts undertaken at the provincial and federal levels described in the previous section, there is little disagreement regarding the major issues affecting the quality of life and well-being of caregivers. Nonetheless, in the interests of ensuring that the Alberta Caregiver Strategy was grounded in the real experiences of Albertan caregivers, the ACGA opted to begin our strategy development process by identifying

the problems that Alberta’s caregivers face. That information was then used to solicit input from caregivers, service providers, and other stakeholders to clarify factors causing or influencing these problems and suggest strategies that could be employed to mitigate these factors and ultimately address the problems. An overview of the consultation and strategy development process is illustrated in the diagram below:



The ACGA worked closely with a Consultation Committee to refine its approach, develop data gathering methods, and solicit input on ways to ensure progress towards the ultimate goal of developing a provincial caregiver strategy. In addition, one-to-one meetings were arranged with key stakeholders to secure support for our efforts and recruit participants for the survey and the conventions.

Consultation Committee

The purpose of the Consultation Committee was to provide guidance on and appropriate linkages to support consultation activities relating to development of the Alberta Caregiver Strategy. The following stakeholders were represented on the Consultation Committee and continue to provide input supporting development of an Alberta Caregiver Strategy:

Stakeholder	Area of Expertise
Alberta Caregivers Association (ACGA)	Caregiving experience; agency serving caregivers in Edmonton
Alberta Health Services (AHS) – Seniors Health	Linkage to public health services
Alberta Disability Forum (ADF)	Disability- and illness-specific organizations
Family Caregiver Centre (Calgary)	Agency serving caregivers in Calgary
Alberta College of Occupational Therapists	Role of professional colleges
University of Alberta (Nursing)	Research on aging and quality of life
University of Calgary (Social Work)	Research on immigrant caregivers
University of Lethbridge (Health Sciences)	Mobilizing support for caregivers in rural areas

Survey

A survey was developed in consultation with committee members to capture the experiences of caregivers by soliciting comments and recollections from caregivers and those with second-hand knowledge (e.g. service providers) regarding challenges, barriers, and other problems. Over 200 people across Alberta participated in the survey.

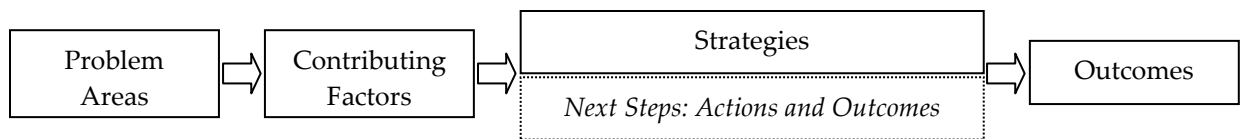
The qualitative (comment box) data was analysed to produce “problem areas”, or key challenges or issues affecting caregivers.

Conventions

Two one-day conventions – one in Calgary for the southern part of the province and the other in Edmonton for the northern part – were organized to bring caregivers, professionals, service providers, and policy makers together. Over 200 people, many from rural communities and smaller urban centres, attended both conventions. In the morning session, delegates were presented with the findings from the survey and asked to identify what factors may contribute to problems faced by caregivers. In the afternoon session, delegates were presented with preliminary findings from the morning session and asked to suggest strategies that could resolve caregiver challenges by addressing contributing factors.

Creating the Strategy Framework

All data collected from the conventions were analysed using adapted qualitative methods to develop sets of contributing factors and categories of strategies based on input from convention delegates. These were then analysed in conjunction with the findings from the survey to draw logical pathways between the problems uncovered in the survey, the factors identified in the morning session of the convention, the strategies suggested in the afternoon session of the convention, and goals (endpoints) derived from the original set of problem areas. This logical pathway provides a framework for the Alberta Caregiver Strategy.



E. Core Beliefs

The following core beliefs were used to guide every aspect of the efforts to achieve a vision of an Alberta where caregivers are valued and supported:

- All caregivers share common needs and strengths despite their varying situations and points on the caregiving journey.
- Caregivers are integral providers of care and therefore are equal members of the care team.
- Acceptance of one’s identity as a caregiver is the first step to seeking help.
- Caregivers need time, energy, money, and support to be able to maintain balance in their lives and participate in community life.

- Varying physical, mental, and emotional challenges necessitate ongoing, comprehensive availability of support to help caregivers cope positively.
- Caregivers need assistance accommodating for their changing roles and identities, including life transitions and the post-caregiver stage.
- The caregiving experience affords caregivers unique perspectives and expertise to plan and provide relevant support for other caregivers.
- Definition and understanding of the caregiver experience is fundamental to developing policies and service systems to meet their needs and those of their loved ones.
- Strong service systems for caregivers and their loved ones are required in communities to make a substantial difference in the lives of caregivers.
- Caregivers require a choice of accessible services (e.g. respite) to maintain their well-being.
- Caregivers need a voice in policy and practice decisions affecting them or their loved ones.

F. A Caregiver Strategy Framework

The consultation process, which acted in many respects as a thorough needs assessment for caregivers in Alberta, identified the following key problem areas:

- Impact of the Caregiver role on relationships with care recipients, family members and friends.
- Balancing the caregiver role and other .life roles.
- Impact of the caregiver role on the health and wellbeing of the caregiver.
- Impact of the caregiver role on the caregiver's work, productivity, education goals and career trajectory.
- Financial costs, financial insecurity, and the lack of financial assistance for caregiving.
- Inconsistency and uncertainty of supports to protect or maintain employment for the caregiver.
- Availability and accessibility of information on service and resources.
- Communication of information on care recipient and resources by ervice providers.
- Difficulty accessing a necessary rang of services in a fragmented system.
- Quality of services provided by the system and community.
- Availability of assistance, help, support and understanding from family, friends and the caregivers community.
- Recognition of the role of caregiver by the system, community and professionals.
- Unavailability of and barriers to accessing respite care when needed.

Appendix 2 - Strategy Framework: Problem Areas, starting on page 12, provides additional details on each of these areas. Appendix 3, starting on page 31, identifies potential strategies and expected outcomes for many of these problem areas. Generally, the key strategies fall into the following groupings:

- Public Education.
- Political Awareness.
- Professional education.
- Family Education.
- Contact and on-going support for caregivers.
- Access to information and resources.
- Access to respite and home care services.
- Improved access to and quality of services, including ensuring sufficient funding levels.

G. Next Steps

This report will be distributed to convention delegates and key stakeholders for their feedback. Consultations with stakeholder groups will be arranged to help fill in any gaps in the framework, secure support for further development of the final strategy document, and mobilize stakeholder resources and interests to promote the strategy. A new coalition, led by the ACGA and comprised of interested stakeholders, will decide on priority areas and develop plans, activities, timelines, and targets to engage public, private, and community stakeholders to implement and adopt the Alberta Caregiver Strategy.

Appendix 1 - Environmental Scan

Shining a Light on Family Caregivers' Issues, Strengths and Needs (Barrett, 2003)

Soon after the ACGA was formed, the founding Board of Directors conducted a needs assessment to determine how best to address the needs of caregivers in Alberta. In 2002, eight focus groups were held through caregiver support groups offered by illness-specific organizations. The results of the study continue to guide the approach taken by the ACGA to this day. Caregivers told us what the ACGA needs to do to help them have a better life:

- Provide peer education and support about the lived experience of being a caregiver.
- Provide specific peer education and support on navigating the service systems involved in the care of family members living with chronic conditions.
- Develop a central resource for primary caregivers and for information about caregivers.
- Advocate for and develop programs that provide a range of appropriate respite for caregivers to enable the healthy coping of the family unit.
- Increase societal understanding of caregivers' role through raising the public profile of primary caregivers and their issues, strengths, and needs.
- Educate health professionals about the caregiver experience and wisdom that primary caregivers have and can contribute as part of the care team.
- Advocate for systems changes to ease the issues faced by caregivers and enhance the quality of life for caregivers and their care recipients.

Unfortunately, the needs expressed by caregivers in 2002 remain relevant in 2011: respite is still lacking, there is only marginal (and unofficial) recognition of the caregiver by service systems, and impacts on caregiver well-being (e.g. maintaining employment, physical and mental health, etc.) are still ignored.

National Conference on Caregiving (October 2005)

In October 2005, the Honourable Tony Ianno, then Minister of State (Families and Caregivers), hosted the National Conference on Caregiving, the first national dialogue on the caregiving issue. Representatives from a wide variety of health, social service, multicultural, business, labour, women's and other groups (including the ACGA) attended this landmark event and contributed their respective areas of expertise and first-hand knowledge as or working with caregivers.

The ACGA presented on the experiences of a provincial caregiving organization, along with the Canadian Caregiver Coalition (CCC) and Providence Healthcare who

presented on the national and municipal perspectives, respectively. Five key themes emerged from the presentations:

- *Recognition and personal support for caregivers.* Caregivers need to be recognized as partners in care and should have a balance of support from community-based providers and their own social networks.
- *Planning and preparation for caregivers.* Caregivers need service providers to orient them to their caregiving role; advisors need to be available to help caregivers navigate their individual journeys.
- *Partnerships.* Caregiver organizations need capacity to make linkages and forge collaborative relationships with service providers and other stakeholders.
- *Supporting diverse groups of caregivers.* Caregiver subpopulations like immigrants/refugees, Aboriginal peoples, those with low-incomes, and those living in remote/rural regions need to be engaged by working with agencies that serve them.
- *Stable funding.* Caregiving organizations need reliable financial support to make up for the “offloading” of caregiver support by institutional and community-based providers.

Conference delegates (more than 215 from across the country) were assigned to working groups to offer their recommendations on what could be done to address issues faced by caregivers. The six focus areas included:

1. Awareness and Recognition
2. Economic Security
3. Employment and Workplace Supports
4. Information and Navigation
5. Respite Supports
6. Strengthening Community Organizations

Several priority issues and recommendations came out of the working group discussions. A summary of the findings is available at the *National Conference on Caregiving - Summary of Proceedings* page on the Human Resources and Skills Development Canada website. The focus areas from the National Conference were used as a foundation for design of the ACGA’s consultation survey, discussed in detail in Part II of this report.

Alberta Disabilities Forum’s Caregiver Community Consultation

In 2008, the Alberta Disabilities Forum (ADF) – a coalition of over thirty provincial disability organizations (including the ACGA) aiming to influence public policy,

educate the public, and share information and resources on issues affecting persons with disabilities – was contracted by Alberta Seniors and Community Supports to conduct consultations on the needs of caregivers of persons with disabilities in fifteen communities across the province. For the most part, participants identified similar challenges to those indicated by their peers in other communities. The ADF's consultations highlighted nine areas that were common issues for caregivers:

1. Finding and retaining well qualified professional caregivers
2. Finding suitable respite services
3. Coping financially
4. Avoiding and dealing with burnout
5. Knowing where to get information and how to navigate the system
6. Obtaining other supports and services, including peer support
7. Coping with the bureaucracy (inflexibility and duplication of efforts)
8. Dealing with a lack of understanding of disabilities and the caregiver role
9. Finding suitable housing, especially for young people

In rural communities and smaller urban centres (i.e. outside Edmonton and Calgary), additional challenges were reported:

- General lack of public transportation
- Shortage of needed services and programs
- Deficiencies in availability of publicly funded housing
- Inequity in choices among urban, rural and Aboriginal caregivers

The ADF's findings provide a supplementary viewpoint of the caregiver issue in Alberta with a focus on those caring for adults living with a disability. The learning from the project and related ADF initiatives was instrumental in formulating the ACGA's consultation strategy, especially in terms of ensuring participation by rural caregivers and encouraging ongoing feedback from key public sector stakeholders.

Roundtables on *A Framework for a Canadian Caregiver Strategy*

Since 2002, the Canadian Caregiver Coalition – “the national body representing and promoting the voice, needs and interests of family caregivers” (Canadian Caregiver Coalition, 2011) – has worked with its community partners to develop national policy that would benefit caregivers across Canada. The culmination of this process was the production of *A Framework for a Canadian Caregiver Strategy* in 2008. It identifies five essential elements of a future national strategy, namely:

- Safeguarding the health and wellbeing of family caregivers and increasing the flexibility and availability of respite care

- Minimizing excessive financial burden placed on family caregivers
- Enabling access to user friendly information and education
- Creating flexible workplace environments that respect caregiving obligations
- Investing in research on family caregiving as a foundation for evidence-informed decision making

In 2009, the ACGA hosted roundtable discussions on the *Framework* document in Edmonton and Calgary with representatives from organizations that have different perspectives on the caregiver issue. These groups included:

- | | | |
|---|---|---|
| ▪ Alberta Disabilities Forum | ▪ Centre for the Cross-Cultural Study of Health and Healing (University of Alberta) | ▪ FCSS Association of Alberta |
| ▪ Alberta Native Friendship Centres Association | ▪ Coalition Femmes de L'Alberta | ▪ Golden Circle Seniors Resource Centre (Red Deer) |
| ▪ ALS Society of Alberta | ▪ Cold Lake Seniors Society | ▪ Heart and Stroke Foundation |
| ▪ Alzheimer Society of Alberta and Northwest Territories | ▪ Department of Family Medicine (University of Alberta) | ▪ Lethbridge Senior Citizens Organization |
| ▪ Alzheimer Society of Calgary | ▪ City of Edmonton FCSS | ▪ Lighthouse Caregiver Group (Barrhead) |
| ▪ Barons-Eureka-Warner Family & Community Support Services (FCSS) | ▪ Edmonton Seniors Coordinating Council | ▪ MS Society of Alberta |
| ▪ Calgary Family Services | ▪ Faculty of Social Work (University of Calgary) | ▪ Multicultural Women and Seniors Association |
| ▪ Calgary Seniors Resource Society | ▪ Family Caregiver Centre (Calgary) | ▪ Research on Aging Policies and Practice Group (University of Alberta) |
| ▪ Canadian Cancer Society | ▪ Family Service Canada | ▪ Schizophrenia Society of Alberta |
| ▪ Canadian Mental Health Association | | ▪ Shepell.fgi |

Delegates at each of the roundtables discussed systemic and societal issues affecting caregivers and clarified the applicability of the five elements of the *Framework* with respect to the Albertan context. There was unanimous support for the following actions:

- Call for endorsement of the CCC *Framework* by community stakeholders and government
- Support the *Alberta Continuing Care Strategy* put forward by Alberta Health & Wellness and Alberta Seniors & Community Supports, particularly its recognition of the need to support caregivers
- Create a provincial voice, led by the ACGA, to take action to create a provincial caregiver strategy that aligns with the CCC's national strategy

The roundtables served to give the ACGA the mandate to lead the process to develop an Alberta Caregiver Strategy. The discussions were also a starting point for the broad-

based, community-driven approach taken in designing and implementing the consultation process.

ACGA Strategic Plan 2010 – 2013

In November 2008, following a period of organizational inactivity and the start of a new Executive Director, the ACGA Board of Directors started a process to collect input from past Board members, volunteers, staff, and program participants in order to set a course for the organization's activities over the short- and medium-term. Focus groups were held to determine the strengths and limitations of the organization in its past and discuss what opportunities and threats existed in its immediate future. Because the ACGA was beginning to become active again and the environment was changing quickly (e.g. economic downturn, other organizations taking on caregiver initiatives), the strategic planning process was stretched over a year and a half to ensure that the Board of Directors was intimately involved in its development and the end product captured the realities of operating within the economic and social climate as it was.

The final version of the plan, approved by the Board of Directors in April 2010, contains a range of goals, objectives, and priority activities of both internal and external scope. One objective in particular set the stage for the ACGA to begin the Alberta Caregiver Strategy consultation process:

Develop a provincial caregiver strategy, incorporating public policy, delivery models, and service provision, through caregiver input, research, expert advice, government participation, and reasonable compromise or consensus among stakeholders.

A selection of objectives relevant to the consultation process and its intended outcome are provided below:

- Engage the general public in order to raise awareness of caregiving issues and facilitate positive and helpful attitudes towards caregivers.
- Engage community organizations, professionals, employers, and other “gatekeepers” to better support caregivers with whom they are already in contact.
- Establish a provincial network of caregiver groups, including Caregiver Networks.
- Facilitate caregiver access to Caregiver Advisors (CA), in essence professionals (or other appropriate individuals) who are trained to address caregivers' needs and prepare them for the journey ahead.
- Develop strong, mutually respectful relationships with government to cooperatively address public policy issues that affect caregivers.
- Lead multi-stakeholder initiatives to present unified positions on public policy, service models, and common practices that affect caregivers.

Appendix 2 - Strategy Framework: Problem Areas → Contributing Factors

<p>Impact of Caregiver Role on Relationships with Care Recipient, Family Members, and Friends</p>	<ul style="list-style-type: none"> ▪ Tensions between caregiver and other family members (spouse, children, siblings, parents) ▪ Caring for care recipient makes it hard to have quality time ▪ Conflicts with family members lead to resentment, anger ▪ Support network of friends shrinks: feel “shunned” by friends and left out of community events ▪ High stress increases risk of abuse, neglect and exploitation ▪ Family members and friends may be available for respite, but may place strain on relationships and reduce support network
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Problem Area

Contributing Factors

- Caregivers have no choice in becoming or continuing as a caregiver, whether their relationship with the person requiring care is positive or negative.
- Caregiving overrides quality time and attention to spouse, children, and other dear ones, resulting in family disharmony, conflict, or dysfunction.
- Caregiving takes over any free time that would be used for personal development and eventually takes time away from essential roles like employment and child care.
- Caring for parents squeezes out time to care for one's children.
- Community members need to be educated on impact of caregiving and how to help caregivers.
- Family members and friends do not understand chronic illness or disability and the associated caregiving burden.
- If the person requiring care did not plan for caregiving, financial liability falls on caregiving family members.
- Maintaining relationships with other family members and friends can be exhausting or impossible.
- Non-caregiving family members can be overbearing, presumptive, hostile, and lack understanding of the real stresses of care.
- Patience and communication skills are negatively affected by stress.
- The care services provided by others invade privacy and disrupt intimate aspects of a loving relationship between the caregiver and the person requiring care.
- The general public has a poor understanding of illness and disability so is uncomfortable facing close acquaintances who experience them.
- The relationship and roles of the caregiver and person requiring care shift and may reverse, producing conflict between them.

Problem Area

Balancing Caregiver Role and Other Life Roles	<ul style="list-style-type: none">▪ Families adapt to another family member's role as caregiver▪ A natural part of the life cycle, but one of the most stressful▪ "Put my life on hold": give up goals, social life, career, being a part of lives of other family members
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Contributing Factors

- Caregivers do not have a choice in becoming a caregiver.
- Caregiving is so sudden and insidious that caregivers do not notice changes in their own health, well-being, or social participation.
- Caregiving overrides quality time and attention to spouse, children, and other dear ones, resulting in family disharmony, conflict, or dysfunction.
- Caregiving takes over any free time that would be used for personal development and eventually takes time away from essential roles like employment and child care.
- Caring for parents squeezes out time to care for one's children.
- Financial insecurity makes meeting necessities difficult and personal enrichment impractical.
- Maintaining relationships with other family members and friends can be exhausting or impossible.
- When employed and caregiving, there is literally no time to care for self; balance is impossible.

Problem Area

Impact of Caregiver Role on Health and Well-Being	<ul style="list-style-type: none">▪ Only energy to make sure care recipient's well-being is maintained and they have meaningful life (but not self)▪ Always worried, feeling guilty, sadness, depression▪ Development of major physical and mental problems▪ High degree of emotional issues: feeling burnt out and hopeless
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Contributing Factors

- Benefits and time off in paid work that are intended for employee self-care are used for caregiving.
- Caregivers are not taught how to care for themselves.
- Caregivers are penalized for being responsible for the person requiring care.
- Caregivers are unwilling to accept respite if there is a risk of a bad experience for the person requiring care.
- Caregivers develop a negative coping mechanism of ignoring their own needs and portraying resiliency because help is unreliable or unavailable.
- Caregivers do not have disposable income for respite or recreation.
- Caregivers do not realize that they deserve self-care and assistance because of societal expectations of independence and resiliency.
- Caregivers have few opportunities to share with and learn from their peers.
- Caregivers have no choice in becoming or continuing as a caregiver, whether their relationship with the person requiring care is positive or negative.
- Caregiver's life is dominated by the person requiring care: no privacy or alone time leads to exhaustion and loss of identity.
- Caregivers may rely on feelings of altruism, sacrifice, or martyrdom to deal with negative effects on their well-being.
- Caregivers need someone to look after the person requiring care in order to have the time to seek out and access resources and services.
- Caregiving diminishes hope for the future because it is uncertain, unpredictable, and scary.
- Caregiving is so sudden and insidious that caregivers do not notice changes in their own health, well-being, or social participation.
- Complicated and lengthy application processes prevent people from being able to access programs that would benefit them.
- Counselling for caregivers is not available, too expensive, or stigmatizing.
- Decreases in service levels and quality increase stress on the caregiver.
- Doctors treat caregivers for psychological disorders or chronic disease without recognizing the impact of caregiver stress.
- Fears of the stigma associated with illness and disability impact perceptions and usage of services on the part of caregivers and persons requiring care.

- Financial insecurity makes meeting necessities difficult and personal enrichment impractical.
- Health service cuts offload burden onto families and persons requiring care.

Problem Area

Impact of Caregiver Role on Health and Well-Being	<ul style="list-style-type: none"> ▪ Only energy to make sure care recipient’s well-being is maintained and they have meaningful life (but not self) ▪ Always worried, feeling guilty, sadness, depression ▪ Development of major physical and mental problems ▪ High degree of emotional issues: feeling burnt out and hopeless
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Contributing Factors (continued)

- It is difficult to recover from effects of caregiving after caregiving has ended.
- It is hard to plan for self-care because caregiving is unpredictable.
- Mental and physical stress diminish ability to follow a healthy lifestyle, which leads to chronic diseases and psychological disorders among caregivers.
- Negative perceptions (true or false) about services and facility care increase reluctance to accept them or use them.
- Professionals, family members, and caregivers themselves do not set realistic expectations of the caregiver's ability to provide care.
- Respite services are geared to assisting with household and care tasks rather than facilitating meaningful time off for the caregiver.
- Services are not available until there is a crisis or emergency.
- Societal and cultural expectations make caregivers feel guilty for not being able to handle the role independently.
- Societal expectations of independence and resiliency increase reluctance to access necessary services.
- Support is not available until the caregiver has a health crisis.
- The caregiver is helpless if the person requiring care does not want to access required services.
- The difficulties associated with trying to access services prevents caregivers from using them.
- The range of services available neglect important psychosocial, vocational, and basic needs of the person requiring care.
- The system's view of a caregiver's capacity and role is not realistic and dehumanizing.
- There is no public recognition of the burden that a person's illness and disability places on his/her caregiver.

Problem Area

Impact on Work Productivity, Education Goals, and Career Trajectory	<ul style="list-style-type: none">▪ Work productivity suffers: exhausted and cannot work efficiently▪ Performing caregiving duties while at work: phone calls to care recipient, booking appointments, etc.▪ Miss out on promotions, pensions, benefits, career development▪ Holding two full-time jobs: paid work plus caregiving responsibilities▪ Take positions that do not offer advancement at low pay and no pension or benefits as trade off for flexibility
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Contributing Factors

- Caregivers do not benefit from job protection if they have to leave their work temporarily to provide care for the person requiring care.
- Caregiving takes over any free time that would be used for personal development and eventually takes time away from essential roles like employment and child care.
- Colleagues at work resent frequent early departures and special treatment, leaving caregiver alienated in workplace.
- Employment insurance is unavailable for temporary but long-term leaves from work for caregiving unless the caregiver's health suffers to the point of disability.
- Financial costs of buying home care services outweighs benefits of employment income.
- Health service cuts offload burden onto families and persons requiring care.
- It is difficult to recover from effects of caregiving after caregiving has ended.
- Suspension of education or career makes for poor employment prospects once caregiving role has been completed.
- The load of caregiving outweighs the personal, social and financial benefits of paid work.
- The unpredictable nature and quasimedical focus of caregiving (as opposed to regular child care) makes it difficult to develop responsive workplace policies.

Problem Area

Financial Costs of Caregiving	<ul style="list-style-type: none">▪ "You just do what you have to do": take a financial hit▪ Having care recipient in assisted living or other placements is like carrying a second mortgage, plus high cost of "add-ons" like laundry, food, medication delivery, bathing▪ Out-of-pocket costs: special diet, home adaptations, travel, and accommodations for treatment in big cities, time off work, medications, home care, wheelchairs and other equipment▪ Cost for in-home care is very expensive
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Contributing Factors

- Accessing any service in rural areas automatically adds transportation costs.
- Doctors may overmedicate persons requiring care but because of a cap on coverage, caregivers end up paying for unnecessary/inappropriate treatment.
- Economic and business factors override the humanitarian goals of health and social services.
- Health service cuts offload burden onto families and persons requiring care.
- Income cutoffs for services are arbitrary and unrealistic.
- Many essential services cost money and are unaffordable.
- People are generally ignorant of real costs or affordability of long-term care at home or in a facility.
- Respite is unavailable, limited, or very costly.
- Services in the community and in care facilities are unaffordable for the average household.
- There is disparity in accessibility and affordability of acute hospital care and care in the community.

Problem Area

Current and Future Financial Insecurity of Caregivers	<ul style="list-style-type: none">▪ Using personal savings, RRSPs for care of care recipient; using savings puts caregiver in jeopardy in the future (retirement)▪ Unable to work or work part-time in low-paying job for flexibility; no financial assistance if leaving paid work▪ Poverty if caregiver is single-parent, elderly, or low-income▪ Concerns about future financial security of care recipient when caregiver not there to cover expenses▪ Not financially able to retire due to caregiving
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Contributing Factors

- Caregivers are deemed financially responsible for the person requiring care and are drained by household income calculations for program or subsidy eligibility.
- Caregivers are penalized for being responsible for the person requiring care.
- Financial planning is not typically available or considered for caregivers despite the universal financial burdens of caring.
- Financial security for the future is ruined by spending all savings to look after the person requiring care.
- If the person requiring care did not plan for caregiving, financial liability falls on caregiving family members.
- People are generally ignorant of real costs or affordability of long-term care at home or in a facility.
- People do not plan ahead for caregiving, and planning is neither straightforward nor possible in many respects.
- Retirement income is reduced due to time away from the labour force.
- Substantial costs for necessary services for the person requiring care reduce caregiver's savings and disposable income, negating financial prudence intended for financial security in old age or support of children.
- Suspension of education or career makes for poor employment prospects once caregiving role has been completed.
- The load of caregiving outweighs the personal, social and financial benefits of paid work.
- There is no income support for caregivers and no other sources of income, making the caregiver dependent on the income of the person requiring care.

Problem Area

Difficulties Finding and Accessing Financial Assistance	<ul style="list-style-type: none">▪ Financial resources available to help with out-of-pocket costs, but hard to find and requires persistence despite setbacks▪ Funding is limited to special groups but still not sufficient▪ Funding available for children disappears once they turn 18▪ Most caregivers not aware of funding programs▪ Funding is structured in a way that prevents many individuals who do not fit from accessing services
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Contributing Factors

- Assertiveness is required to get services, but can result in being labeled as a troublemaker.
- Caregivers are burdened by lengthy and complicated application processes that only appear to act as deterrents to limit the number of people who access funding.
- Caregivers are not given an orientation, information, or assistance in understanding and navigating the system.
- Complicated and lengthy application processes prevent people from being able to access programs that would benefit them.
- Income cutoffs for services are arbitrary and unrealistic.
- Self-managed care funding cannot be used for family members.
- The person requiring care becomes a very costly dependent with few tax breaks that do not reflect actual expense on the part of the caregiver.
- The system is structured so that exclusive eligibility criteria or specific diagnoses determine access to a basket of services, rather than providing services based on individual need.

Problem Area

Inconsistency and Uncertainty of Supports to Protect or Maintain Employment	<ul style="list-style-type: none">▪ Professionals, service providers, government, employers, and general public do not recognize role of caregivers▪ Job worries because taking too much time off for caregiving and emergencies▪ Many supportive supervisors/employers and work environments, but uncertainty about extent of concessions▪ No protection from being fired for needing time to care for care recipient▪ Use all holidays and personal days to care for care recipient: burnt out and stressed
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Contributing Factors

- Benefits and time off in paid work that are intended for employee self-care are used for caregiving.
- Caregivers do not benefit from job protection if they have to leave their work temporarily to provide care for the person requiring care.
- Colleagues at work resent frequent early departures and special treatment, leaving caregiver alienated in workplace.
- Employment insurance is unavailable for temporary but long-term leaves from work for caregiving unless the caregiver's health suffers to the point of disability.
- Financial costs of buying home care services outweighs benefits of employment income.
- The load of caregiving outweighs the personal, social and financial benefits of paid work.
- The unpredictable nature and quasimedical focus of caregiving (as opposed to regular child care) makes it difficult to develop responsive workplace policies.
- When employed and caregiving, there is literally no time to care for self; balance is impossible.

Problem Area

Availability and Accessibility of Information on Services & Resources	<ul style="list-style-type: none">▪ Caregiver may be provided with initial information but then left to “muddle through”▪ Government websites are difficult to navigate and lead caregivers to out-of-date, inappropriate, or missing content▪ Too much focus on internet; seniors and low-income people may not have computers▪ Information on services in rural areas mainly passed through word-of-mouth; no directories like in big cities▪ Difficulties finding, accessing, and understanding range of programs available
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Contributing Factors

- Caregivers have few opportunities to share with and learn from their peers.
- Caregivers need someone to look after the person requiring care in order to have the time to seek out and access resources and services.
- Essential information is not consistently or reliably shared among professionals or with caregivers.
- Information on services is unreliable and often incomplete.
- No reliable source of information and assistance for caregivers.
- No training or preparation is provided to caregivers even though their responsibility is comparable to health professionals.
- Professionals are not educated on services outside the scope of their practice but relevant to the needs of their clients.
- Professionals are not trained to recognize or support caregivers.
- The system's focus on web-based resources neglects needs for information in print and other accessible media.
- There is limited continuity between the hospital and the community.
- There is no advisor or guide to help caregivers manage the work they do for the person requiring care and what they do to care for themselves.
- There is too much reliance on websites for information dissemination, without provision of equivalent information in other more accessible media.

Problem Area

Communication of Information on Care Recipient and Resources by Service Providers	<ul style="list-style-type: none">▪ Protection of privacy for care recipient conflicts with caregiver's need for information; care recipients may not understand or choose not to pass on information▪ Communication among providers (e.g. doctors, allied professionals, support workers) inadequate▪ Response time to information requests can be very long if they respond at all: problematic especially in crises or emergencies▪ Staff too busy, sometimes provide misinformation or inappropriate referrals▪ Information and support services provided by community organizations are difficult to get in rural areas because of costs
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Contributing Factors

- Caregivers are not given an orientation, information, or assistance in understanding and navigating the system.
- Caregivers need someone to look after the person requiring care in order to have the time to seek out and access resources and services.
- Doctors are not always available or able to commit the time to dealing with complex issues, but they are critical gatekeepers to other services.
- Essential information is not consistently or reliably shared among professionals or with caregivers.
- Information on services is unreliable and often incomplete.
- No training or preparation is provided to caregivers even though their responsibility is comparable to health professionals.
- Professionals are not educated on services outside the scope of their practice but relevant to the needs of their clients.
- Professionals are not trained to recognize or support caregivers.
- Professionals are not trained to work with others, including caregivers.
- The system is complicated and lacks transparency or order.
- The system is controlled from the top down, segregated using arbitrary divisions, and excludes outsiders including caregivers and community providers.
- There is limited continuity between the hospital and the community.

Problem Area

Difficulty Getting Necessary Range of Services in Fragmented System	<ul style="list-style-type: none">▪ Resourcefulness and persistence of caregivers are determining factors in their ability to get information and resources▪ Difficulty accessing services because care recipient feels they do not need help or do not want to be labelled as “disabled”▪ Lack of case management for the caregiver and ensuring continuity across different providers▪ Lack of housing and services for younger adults and those with some conditions (dementia, mental health, comorbidity)▪ Immigrants and transient populations do not know how to access services▪ Very few services directly for caregiver needs; caregivers need to search themselves for support groups and other assistance▪ Large discrepancy between availability in cities vs. rural areas
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Contributing Factors

- Accessing any service in rural areas automatically adds transportation costs.
- Assertiveness is required to get services, but can result in being labeled as a troublemaker.
- Caregiver needs are not systematically assessed nor addressed.
- Caregivers are not considered in health planning.
- Caregivers are not given an orientation, information, or assistance in understanding and navigating the system.
- Caregivers are not recognized as legitimate service providers.
- Case management and coordination are essential to managing the range of hospital- and community-based services required for chronic conditions, but are a rarity and only available under special circumstances.
- Complicated and lengthy application processes prevent people from being able to access programs that would benefit them.
- Different parts of the public system compete for the same decreasing pool of funds.
- Doctors are not always available or able to commit the time to dealing with complex issues, but they are critical gatekeepers to other services.
- Essential information is not consistently or reliably shared among professionals or with caregivers.
- Income cutoffs for services are arbitrary and unrealistic.
- Information on services is unreliable and often incomplete.
- Necessities like housing, transportation, and income support are excluded from the scope of care planning.
- Negative perceptions (true or false) about services and facility care increase reluctance to accept them or use them.
- No reliable source of information and assistance for caregivers.

- Professionals are not educated on services outside the scope of their practice but relevant to the needs of their clients.
- Professionals are not trained to work with others, including caregivers.
- Program funding is volatile and unpredictable.

Problem Area

Difficulty Getting Necessary Range of Services in Fragmented System	<ul style="list-style-type: none"> ▪ Resourcefulness and persistence of caregivers are determining factors in their ability to get information and resources ▪ Difficulty accessing services because care recipient feels they do not need help or do not want to be labelled as “disabled” ▪ Lack of case management for the caregiver and ensuring continuity across different providers ▪ Lack of housing and services for younger adults and those with some conditions (dementia, mental health, comorbidity) ▪ Immigrants and transient populations do not know how to access services ▪ Very few services directly for caregiver needs; caregivers need to search themselves for support groups and other assistance ▪ Large discrepancy between availability in cities vs. rural areas
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Contributing Factors (continued)

- Rural areas do not have the range of services that exist in urban areas.
- Services are delivered based on arbitrary criteria like age, even when the condition of the person requiring care is not dependent on these criteria.
- Services are not available until there is a crisis or emergency.
- Services do not take into account barriers associated with cultural or linguistic backgrounds of persons requiring care and caregivers.
- Support is not available until the caregiver has a health crisis.
- The "system" is more of a patchwork of isolated programs than a carefully designed service system.
- The caregiver is helpless if the person requiring care does not want to access required services.
- The system is complicated and lacks transparency or order.
- The system is controlled from the top down, segregated using arbitrary divisions, and excludes outsiders including caregivers and community providers.
- The system is structured so that exclusive eligibility criteria or specific diagnoses determine access to a basket of services, rather than providing services based on individual need.
- The system's view of a caregiver's capacity and role is not realistic and dehumanizing.
- There is a general lack of illness-specific organizations and support groups in rural areas.
- There is disparity in accessibility and affordability of acute hospital care and care in the community.
- There is inconsistency in the quality and availability of services from one region to another.
- There is limited continuity between the hospital and the community.

- There is no recourse for caregivers or persons requiring care that receive ill-treatment or poor service.

Problem Area

<p>Quality of Services Provided by the System and in the Community</p>	<ul style="list-style-type: none"> ▪ Staffing shortages make it hard for them to answer questions or follow-up ▪ Delays between testing, assessments, treatment planning, access to services ▪ Limited staffing in care facilities results in caregiver continuing role in care ▪ Care workers: shortages and turnover, overworked and underpaid, burned out, not kept in loop, limited training ▪ Care recipients may not want respite because facility environment is not suitable or comfortable ▪ Community organizations do not have the financial and human resources to meet all the need they are trying to address with their valuable programs ▪ Community-based supports are inconsistent and cannot replace formal services
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Contributing Factors

- Caregivers are not considered in health planning.
- Caregivers are not recognized as legitimate service providers.
- Community-based organizations are always struggling for funding to maintain service levels and retain staff who are paid less than similar positions in the system.
- Different parts of the public system compete for the same decreasing pool of funds.
- Doctors are not always available or able to commit the time to dealing with complex issues, but they are critical gatekeepers to other services.
- Doctors treat caregivers for psychological disorders or chronic disease without recognizing the impact of caregiver stress.
- Economic and business factors override the humanitarian goals of health and social services.
- Frontline non-professional workers have inconsistent training, qualifications, and experience.
- Frontline non-professional workers receive low pay and work under suboptimal working conditions.
- Inconsistent quality of home and respite care reduces trust or confidence in services on the part of the person requiring care and the caregiver.
- It is hard to find home care workers who meet requirements and will stay in the job for an extended period of time.
- Persons requiring care are sent home to free up acute care beds, even though the reasons for admission may still be present and care needs may still heavy.
- Program funding is volatile and unpredictable.
- Services are not available until there is a crisis or emergency.
- Staff working in the system are always expected to do more with less.
- Support groups that meet the needs of caregivers and cater to their strengths are hard to find.
- Support is not available until the caregiver has a health crisis.

- The "system" is more of a patchwork of isolated programs than a carefully designed service system.
- The economic benefit of the care provided by caregivers is not recognized in system planning.

Problem Area

Quality of Services Provided by the System and in the Community	<ul style="list-style-type: none"> ▪ Staffing shortages make it hard for them to answer questions or follow-up ▪ Delays between testing, assessments, treatment planning, access to services ▪ Limited staffing in care facilities results in caregiver continuing role in care ▪ Care workers: shortages and turnover, overworked and underpaid, burned out, not kept in loop, limited training ▪ Care recipients may not want respite because facility environment is not suitable or comfortable ▪ Community organizations do not have the financial and human resources to meet all the need they are trying to address with their valuable programs ▪ Community-based supports are inconsistent and cannot replace formal services
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Contributing Factors (continued)

- The life of the person requiring care is continued even when quality of life is atrocious, mortality is a short-term eventuality, and there is no hope for recovery.
- The range of services available neglect important psychosocial, vocational, and basic needs of the person requiring care.
- The system is complicated and lacks transparency or order.
- The system is controlled from the top down, segregated using arbitrary divisions, and excludes outsiders including caregivers and community providers.
- The system is structured so that exclusive eligibility criteria or specific diagnoses determine access to a basket of services, rather than providing services based on individual need.
- The system's view of a caregiver's capacity and role is not realistic and dehumanizing.
- There is limited continuity between the hospital and the community.
- There is no recourse for caregivers or persons requiring care that receive ill-treatment or poor service.

Problem Area

Availability of Support and Understanding From Own Community	<ul style="list-style-type: none">▪ People understand importance of child care, but not care for elderly or disabled▪ Public sees role as simply supervision: not aware of complexity, intensity, and stresses▪ Professionals, service providers, government, employers, and general public do not recognize role of caregivers▪ Public is not prepared for caregiving because they are unaware of its consequences▪ Same needs as child care – flexibility in hours, need for support and day care – but not seen in the same way▪ Negative stigma associated with being a caregiver▪ Smaller rural communities may be better than larger ones at rallying community support
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Contributing Factors

- Caregiver needs are not systematically assessed nor addressed.
- Caregivers are not considered in health planning.
- Caregivers are not recognized as legitimate service providers.
- Caregivers are unwilling to reveal private family matters in order to access help.
- Caregivers feel like they are the only one the person requiring care can count on.
- Caregivers need someone to look after the person requiring care in order to have the time to seek out and access resources and services.
- Doctors are not always available or able to commit the time to dealing with complex issues, but they are critical gatekeepers to other services.
- Negative perceptions (true or false) about services and facility care increase reluctance to accept them or use them.
- Respite is oriented around the needs of persons requiring care and their willingness to accept it, not necessarily the caregivers' need.
- Respite services are geared to assisting with household and care tasks rather than facilitating meaningful time off for the caregiver.
- Rural areas do not have the range of services that exist in urban areas.
- The economic benefit of the care provided by caregivers is not recognized in system planning.
- The onus is on the caregiver to ask for help because others may not offer.
- The system is structured so that exclusive eligibility criteria or specific diagnoses determine access to a basket of services, rather than providing services based on individual need.
- The system's view of a caregiver's capacity and role is not realistic and dehumanizing.
- There is no public recognition of the burden that a person's illness and disability places on his/her caregiver.

Problem Area

Availability of Help From Family and Friends	<ul style="list-style-type: none">▪ Other family members not available, especially if they live out of town or have busy lives▪ Caregivers have difficulty knowing who to ask for help▪ Family members and friends may be available for respite, but may place strain on relationships and reduce support network▪ Faith communities provide emotional support, but difficult to access practical support
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Contributing Factors

- Caregivers are unwilling to reveal private family matters in order to access help.
- Caregivers develop a negative coping mechanism of ignoring their own needs and portraying resiliency because help is unreliable or unavailable.
- Caregivers do not realize that they deserve self-care and assistance because of societal expectations of independence and resiliency.
- Caregivers feel like they are the only one the person requiring care can count on.
- Caregivers need someone to look after the person requiring care in order to have the time to seek out and access resources and services.
- Community members need to be educated on impact of caregiving and how to help caregivers.
- Ensuring the privacy of the person requiring care trumps offers of help from family and friends.
- Family and friends have their own busy lives so are unable to assist in caregiving.
- Family and friends who may want to help do not know how to help.
- Family members and friends do not understand chronic illness or disability and the associated caregiving burden.
- Family support in rural areas is diminished by mobility of family members to urban areas.
- It is hard to earn support from community members when a caregiver is no longer contributing to the community.
- Maintaining relationships with other family members and friends can be exhausting or impossible.
- Non-caregiving family members can be overbearing, presumptive, hostile, and lack understanding of the real stresses of care.
- Societal and cultural expectations make caregivers feel guilty for not being able to handle the role independently.
- Societal expectations of independence and resiliency increase reluctance to access necessary services.

- The general public has a poor understanding of illness and disability so is uncomfortable facing close acquaintances who experience them.
- The onus is on the caregiver to ask for help because others may not offer.
- There is no public recognition of the burden that a person's illness and disability places on his/her caregiver.

Problem Area

Recognition of Caregiver by the System and Professionals	<ul style="list-style-type: none"> ▪ Concern that awareness is there, but being “swept under the rug” by government; saving from cuts passes costs to caregivers ▪ Professionals, service providers, government, employers, and general public do not recognize role of caregivers ▪ Value is not given to caregivers; belittled by the system ▪ Professionals do not recognize that their contribution is brief and limited compared to 24-hour responsibility of caregiver
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Contributing Factors

- Caregiver needs are not systematically assessed nor addressed.
- Caregivers are not considered in health planning.
- Caregivers are not recognized as legitimate service providers.
- Professionals are not educated on services outside the scope of their practice but relevant to the needs of their clients.
- Professionals are not trained to recognize or support caregivers.
- Professionals are not trained to work with others, including caregivers.
- Professionals, family members, and caregivers themselves do not set realistic expectations of the caregiver's ability to provide care.
- The system's view of a caregiver's capacity and role is not realistic and dehumanizing.
- There is no recourse for caregivers or persons requiring care that receive ill-treatment or poor service.

Problem Area

Unavailability and Barriers to Accessing Respite Care When Needed	<ul style="list-style-type: none">▪ Caregivers need emotional support to accept respite and overcome feelings of guilt▪ Long waiting list for respite beds and not available when needed▪ Respite not available on short notice or in emergency situations, such as when the caregiver is sick or dies▪ Respite not available for all caregivers▪ Difficulties finding care that caregiver trusts and feels comfortable leaving care recipient▪ Few respite beds in “nice home setting” for comfort of care recipient and peace of mind of caregiver▪ Respite outside normal working hours is difficult to obtain
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Contributing Factors

- Caregivers are not prepared for the demands of the caregiving role.
- Caregivers are unwilling to accept respite if there is a risk of a bad experience for the person requiring care.
- Caregivers develop a negative coping mechanism of ignoring their own needs and portraying resiliency because help is unreliable or unavailable.
- Caregivers need someone to look after the person requiring care in order to have the time to seek out and access resources and services.
- It is hard to plan for self-care because caregiving is unpredictable.
- Respite is not available on short notice or in times of crisis or emergency.
- Respite is oriented around the needs of persons requiring care and their willingness to accept it, not necessarily the caregivers' need.
- Respite is unavailable, limited, or very costly.
- Respite services are geared to assisting with household and care tasks rather than facilitating meaningful time off for the caregiver.
- There is no automatic planning of long-term respite needs for caregivers.
- There is no sanctuary for caregivers.

Appendix 3 - Strategies and Outcomes

Strategies		Draft Outcomes (from Problem Areas)
Public Education	<i>Implement public awareness campaigns on health conditions and caregiving.</i>	<p>Caregivers' work productivity, education goals, and career trajectory are not negatively impacted by their caregiving role.</p> <p>Caregivers get support and understanding from the communities in which they live.</p> <p>Help is available from family and friends or other sources if family and friends are not available.</p>
	<i>Include education on caregiving in school.</i>	<p>Caregivers' health and well-being does not deteriorate because of their role.</p>
	<i>Provide education on caregiving to people in contact with caregivers.</i>	<p>Caregivers' relationships with the person requiring care, family members, and friends are not negatively impacted by the caregiving role.</p> <p>Caregivers get support and understanding from the communities in which they live.</p> <p>Help is available from family and friends or other sources if family and friends are not available.</p>
Political Awareness	<i>Build an awareness of caregiving issues in the political domain.</i>	<p>Caregivers' health and well-being does not deteriorate because of their role.</p> <p>Caregivers' work productivity, education goals, and career trajectory are not negatively impacted by their caregiving role.</p> <p>Financial costs of caregiving are not a hardship on caregivers.</p> <p>Service providers provide caregivers with information they need on the person requiring care and available resources.</p> <p>Caregivers are able to get all the services that they and the person requiring care need without difficulty.</p> <p>Caregivers get support and understanding from the communities in which they live.</p> <p>The caregiver role is recognized and valued by the system and service providers.</p>
Professional Education	<i>Recognize that caregivers are an integral part of the care team.</i>	<p>Information on services and resources is available and accessible.</p> <p>Service providers provide caregivers with information they need on the person requiring care and available resources.</p> <p>Caregivers are able to get all the services that they and the person requiring care need without difficulty.</p> <p>Appropriate and sufficient services are provided by the system and in the community.</p> <p>Caregivers get support and understanding from the communities in which they live.</p>
	<i>Provide training on significance, impact, and lived experience of caregivers.</i>	<p>Caregivers' health and well-being does not deteriorate because of their role.</p> <p>Caregivers are able to get all the services that they and the person requiring care need without difficulty.</p> <p>Appropriate and sufficient services are provided by the system and in the community.</p>

Professional Education (con't)	<i>Teach professionals how to work with others, including caregivers.</i>	<p>Service providers provide caregivers with information they need on the person requiring care and available resources.</p> <p>Caregivers are able to get all the services that they and the person requiring care need without difficulty.</p> <p>Appropriate and sufficient services are provided by the system and in the community.</p> <p>The caregiver role is recognized and valued by the system and service providers.</p>
Family Education	<i>Enable families to plan for caregiving in the future.</i>	<p>Caregivers are able to balance the caregiver role with other life roles.</p> <p>Financial costs of caregiving are not a hardship on caregivers.</p> <p>Caregiving does not negatively impact current or future financial security of caregivers or their families.</p>
	<i>Provide tools for families and caregivers to educate themselves.</i>	<p>Caregivers' relationships with the person requiring care, family members, and friends are not negatively impacted by the caregiving role.</p> <p>Help is available from family and friends or other sources if family and friends are not available.</p>
	<i>Provide training and resources so that the caregiver is able to provide quality care.</i>	<p>Information on services and resources is available and accessible.</p>
Initial Contact and Ongoing Support	<i>Include caregiver support in patient care planning.</i>	<p>Caregivers' health and well-being does not deteriorate because of their role.</p> <p>Caregivers are able to get all the services that they and the person requiring care need without difficulty.</p> <p>The caregiver role is recognized and valued by the system and service providers.</p> <p>Meaningful respite is available to caregivers when they need it.</p>
	<i>Offer better case management and navigation services.</i>	<p>Caregivers are able to find and access financial assistance without difficulty.</p> <p>Information on services and resources is available and accessible.</p> <p>Service providers provide caregivers with information they need on the person requiring care and available resources.</p> <p>Caregivers are able to get all the services that they and the person requiring care need without difficulty.</p>
Initial Contact and Ongoing Support (continued)	<i>Provide an orientation and ongoing support for caregivers.</i>	<p>Caregivers' relationships with the person requiring care, family members, and friends are not negatively impacted by the caregiving role.</p> <p>Caregivers are able to balance the caregiver role with other life roles.</p> <p>Caregivers' health and well-being does not deteriorate because of their role.</p> <p>Caregivers get support and understanding from the communities in which they live.</p> <p>Meaningful respite is available to caregivers when they need it.</p>
	<i>Provide Caregiver Advisors and patient navigators.</i>	<p>Caregivers' health and well-being does not deteriorate because of their role.</p> <p>Caregiving does not negatively impact current or future financial security of caregivers or their families.</p> <p>Caregivers are able to find and access financial assistance without difficulty.</p> <p>Information on services and resources is available and accessible.</p> <p>Caregivers are able to get all the services that they and the person requiring care need without difficulty.</p>

	<i>Use physicians to connect caregivers to support.</i>	Caregivers' health and well-being does not deteriorate because of their role. Service providers provide caregivers with information they need on the person requiring care and available resources.
Access to Information and Resources	<i>Ease entry into and referrals through system.</i>	Caregivers' health and well-being does not deteriorate because of their role. Caregivers are able to find and access financial assistance without difficulty.
	<i>Provide an up-to-date and accessible central repository of information on services.</i>	Information on services and resources is available and accessible. Caregivers are able to get all the services that they and the person requiring care need without difficulty.
	<i>Offer a hotline for caregivers to call.</i>	Information on services and resources is available and accessible.
Access to Respite and Home Care Services	<i>Ensure respite and home care services are flexible to give caregivers meaningful time off.</i>	Caregivers' relationships with the person requiring care, family members, and friends are not negatively impacted by the caregiving role. Caregivers are able to balance the caregiver role with other life roles. Caregivers' health and well-being does not deteriorate because of their role. Meaningful respite is available to caregivers when they need it.
	<i>Make respite and home care services affordable.</i>	Financial costs of caregiving are not a hardship on caregivers.
Access to Respite and Home Care Services (continued)	<i>Provide a range of respite and home care services based on needs of caregivers and persons requiring care.</i>	Caregivers' relationships with the person requiring care, family members, and friends are not negatively impacted by the caregiving role. Caregivers are able to balance the caregiver role with other life roles. Caregivers' health and well-being does not deteriorate because of their role. Caregivers get support and understanding from the communities in which they live. Meaningful respite is available to caregivers when they need it.
	<i>Provide respite and home care services based on caregiver needs.</i>	Caregivers are able to balance the caregiver role with other life roles. Caregivers get support and understanding from the communities in which they live. Meaningful respite is available to caregivers when they need it.
Employment and Financial Security	<i>Offer caregiver employment insurance and protection for compassionate leave</i>	Caregivers' health and well-being does not deteriorate because of their role. Caregivers' work productivity, education goals, and career trajectory are not negatively impacted by their caregiving role.
	<i>Provide financial compensation for caregiving costs.</i>	Caregivers' relationships with the person requiring care, family members, and friends are not negatively impacted by the caregiving role. Caregivers are able to balance the caregiver role with other life roles. Caregivers' health and well-being does not deteriorate because of their role. Caregivers' work productivity, education goals, and career trajectory are not negatively impacted by their caregiving role. Caregiving does not negatively impact current or future financial security of caregivers or their families. Caregivers are able to find and access financial assistance without difficulty.

	<i>Stop penalizing caregivers for not being able to participate in the workforce.</i>	Caregivers' work productivity, education goals, and career trajectory are not negatively impacted by their caregiving role. Caregiving does not negatively impact current or future financial security of caregivers or their families.
Caregiver Support	<i>Bring caregivers together for peer support.</i>	Caregivers' health and well-being does not deteriorate because of their role. Information on services and resources is available and accessible. Help is available from family and friends or other sources if family and friends are not available.
Caregiver Support (continued)	<i>Provide counselling and family therapy.</i>	Caregivers' relationships with the person requiring care, family members, and friends are not negatively impacted by the caregiving role. Caregivers are able to balance the caregiver role with other life roles. Caregivers' health and well-being does not deteriorate because of their role.
	<i>Teach caregivers how to care for themselves.</i>	Caregivers' health and well-being does not deteriorate because of their role. Caregivers get support and understanding from the communities in which they live. Help is available from family and friends or other sources if family and friends are not available. Meaningful respite is available to caregivers when they need it.
Recourse for Caregivers	<i>Establish a caregiver advocate and/or ombudsman for families accessing the system.</i>	Information on services and resources is available and accessible. The caregiver role is recognized and valued by the system and service providers. Caregivers are able to get all the services that they and the person requiring care need without difficulty. Appropriate and sufficient services are provided by the system and in the community.
	<i>Implement mechanism for confidential feedback from caregivers.</i>	Caregivers are able to get all the services that they and the person requiring care need without difficulty. Appropriate and sufficient services are provided by the system and in the community.
Diversity of Caregivers	<i>Consider needs of children in caregiving situations.</i>	Caregivers' relationships with the person requiring care, family members, and friends are not negatively impacted by the caregiving role. Caregivers are able to balance the caregiver role with other life roles.
	<i>Account for cultural diversity in Alberta.</i>	Caregivers are able to get all the services that they and the person requiring care need without difficulty.
Community-based Supports	<i>Provide funding for non-profits to offer caregiver programs.</i>	Appropriate and sufficient services are provided by the system and in the community.
	<i>Reduce disparities among community-based providers.</i>	Caregivers are able to get all the services that they and the person requiring care need without difficulty. Appropriate and sufficient services are provided by the system and in the community.

	<i>Mobilize community members to support caregivers.</i>	Caregivers get support and understanding from the communities in which they live. Help is available from family and friends or other sources if family and friends are not available.
Frontline Staffing	<i>Ensure appropriate training and accreditation of frontline care staff.</i>	Appropriate and sufficient services are provided by the system and in the community.
	<i>Pay care workers equitably.</i>	Appropriate and sufficient services are provided by the system and in the community.
Equitable Access to Services	<i>Ensure consistent and equitable service delivery for all Albertans.</i>	Caregivers are able to get all the services that they and the person requiring care need without difficulty.
	<i>Increase services in rural areas.</i>	Caregivers are able to get all the services that they and the person requiring care need without difficulty. Caregivers get support and understanding from the communities in which they live. Help is available from family and friends or other sources if family and friends are not available.
	<i>Provide transportation and accommodation for appointments for families living in rural communities.</i>	Financial costs of caregiving are not a hardship on caregivers. Caregivers are able to get all the services that they and the person requiring care need without difficulty.
Sufficiency of Funding	<i>Improve community support services and facility care.</i>	Caregivers' health and well-being does not deteriorate because of their role. Financial costs of caregiving are not a hardship on caregivers. Caregivers are able to get all the services that they and the person requiring care need without difficulty. Appropriate and sufficient services are provided by the system and in the community. Caregivers get support and understanding from the communities in which they live.
	<i>Allocate more health funding to front-line staff.</i>	Appropriate and sufficient services are provided by the system and in the community.
	<i>Provide necessary services based on need, not diagnosis.</i>	Caregivers are able to find and access financial assistance without difficulty. Caregivers are able to get all the services that they and the person requiring care need without difficulty. Appropriate and sufficient services are provided by the system and in the community. Caregivers get support and understanding from the communities in which they live.

<p>Sufficiency of Funding (continued)</p>	<p><i>Ensure funding is able to meet needs of service users.</i></p>	<p>Financial costs of caregiving are not a hardship on caregivers.</p> <p>Caregiving does not negatively impact current or future financial security of caregivers or their families.</p> <p>Caregivers are able to find and access financial assistance without difficulty.</p> <p>Caregivers are able to get all the services that they and the person requiring care need without difficulty.</p> <p>Appropriate and sufficient services are provided by the system and in the community.</p>
<p>System Overhaul</p>	<p><i>Appreciate practical expertise of caregivers.</i></p>	<p>Appropriate and sufficient services are provided by the system and in the community.</p>
	<p><i>Change the system so it reflects the needs of caregivers and persons requiring care.</i></p>	<p>Caregivers' health and well-being does not deteriorate because of their role.</p> <p>Financial costs of caregiving are not a hardship on caregivers.</p> <p>Caregivers are able to find and access financial assistance without difficulty.</p> <p>Service providers provide caregivers with information they need on the person requiring care and available resources.</p> <p>Caregivers are able to get all the services that they and the person requiring care need without difficulty.</p> <p>Appropriate and sufficient services are provided by the system and in the community.</p>
	<p><i>Ensure services are individualized and comprehensive.</i></p>	<p>Caregivers' health and well-being does not deteriorate because of their role.</p> <p>Information on services and resources is available and accessible.</p> <p>Caregivers are able to get all the services that they and the person requiring care need without difficulty.</p>
	<p><i>Make system accountable for well-being of caregivers.</i></p>	<p>Caregivers' health and well-being does not deteriorate because of their role.</p> <p>Appropriate and sufficient services are provided by the system and in the community.</p> <p>The caregiver role is recognized and valued by the system and service providers.</p>