The Evaluation of Ontario’s Strategy for Alzheimer Disease and Related Dementias
Final Report

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EXECUTIVE SUMMARY

Background

In 1999, the government announced Ontario's Strategy for Alzheimer Disease and Related Dementias (ADRD). The Strategy was the first comprehensive strategy on Alzheimer Disease in Canada with a total of $68.4 million invested between 1999 and 2004. The Strategy included ten specific but related initiatives aimed at improving the quality of life of people with ADRD and their caregivers in Ontario. The initiatives involved:

- education for health care providers, caregivers and the public;
- service enhancements and expansion; and
- research activities and knowledge exchange.

The Strategy was a joint initiative between the Ministry of Health and Long-Term Care and the Ontario Seniors' Secretariat, part of the Ministry of Citizenship and Immigration.

Evaluation of the Alzheimer Strategy

An independent Evaluator was hired to evaluate the overall Alzheimer Strategy and each of its initiatives. Evaluation activities began in 2001 with the Evaluator developing specific evaluation plans in collaboration with individual initiative Working Groups. As much as possible, the focus of the evaluation was on assessing outcomes of the individual initiatives and the overall Strategy.

This report provides a summary of the results from the overall Alzheimer Strategy evaluation. Details about the implementation of the Strategy and activities undertaken to help sustain the gains from the Strategy are also discussed.

Four overall goals of the Alzheimer Strategy were identified and subsequently used to assess the success of the Strategy. These were:

1. to support and improve the quality of life of people with ADRD and their caregivers;
2. to improve treatment, care and environmental conditions of people with ADRD;
3. to increase public awareness of dementia and the services available; and
4. to develop linkages between the initiatives within the Strategy.

Data from the overall Strategy evaluation and the initiative specific evaluations indicated that the four goals of the Strategy had been met. Participants in the overall evaluation reported that the Strategy contributed to improvements in quality of life and treatment and care for people with ADRD, as well as greater public awareness of ADRD and the services available. They also reported that numerous linkages among the Strategy initiatives had been forged.

In addition to these goals, the Strategy led to various collaborations within the system of care that resulted in benefits for people with ADRD and their caregivers, service providers and organizations, advocacy groups, and the care system. These collaborations were identified as one of the key strengths of the Strategy.

Some limitations and/or areas for improvement related to the Strategy were also identified. These included: issues related to the planning and implementation of the Strategy, shortcomings of certain Strategy initiatives, and other limitations related to the allocation of resources and funding.

The primary concern raised in relation to the Alzheimer Strategy was that of sustainability. The majority of stakeholders interviewed regarding the impact of the overall Strategy were concerned that the many benefits realized as a result of the Strategy would not be maintained and supported.

Stakeholders identified the following as necessary for sustainability:

- continued support for specific initiatives, especially those aimed at improving information sharing and knowledge about ADRD, improving caregiving skills, and enhancing service delivery;
- a commonly agreed upon framework and vision for supporting ongoing activities;
- the integration of the achievements of the Strategy into daily practice (i.e., standards regarding the implementation of new knowledge into practice, organizational support to ensure sustainability); and
- mechanisms for evaluation, research, and the dissemination of new information.

Alzheimer Strategy Evaluation Process

There were many positive aspects to the Alzheimer Strategy evaluation including: the government's commitment to having the Alzheimer Strategy evaluated; the focus on outcomes; the collaboration between the Evaluator, the government, various Working Groups and those involved in the Strategy initiatives; and the use of a multi-pronged evaluation approach. In addition to these advantages, there were also some limitations / areas for improvement related to the Alzheimer Strategy evaluation. These included: limits in terms of the evaluation design; the measurement of the overall goals of the Alzheimer Strategy; obtaining buy-in regarding the importance of the evaluation; working with multiple stakeholders; sharing evaluation results; and conducting long-term follow-ups as part of the evaluation.

Implementation of the Strategy

Those who participated in the evaluation of the overall Alzheimer Strategy made a number of comments about how the Strategy was implemented. While a few shortcomings were identified, the majority of comments were positive. Specifically, participants commented on the strengths related to the planning of the Strategy (e.g., extensive consultation with stakeholders; interministerial approach; comprehensiveness of the Strategy; interdisciplinary nature of the Strategy; and the importance given to the evaluation) as well as the implementation of the Strategy (e.g., dedication of human and fiscal resources; multi-level linkages; shared vision and commitment of those involved in the Strategy; and specific initiatives such as staff education, physician education, the Psychogeriatric Resource Consultants, Public Education Coordinators, and Dementia Networks).

Sustainability Efforts

Because of their desire to ensure that the benefits realized as a result of the Strategy would continue and expand, the External Advisory Committee endorsed a plan that recommended certain supports be in place at the end of the Strategy's implementation period. These supports included:

- **Initiative Representative Work Group** – the role of this group was to oversee the promotion, coordination and integration of the Alzheimer Strategy initiatives and to identify, advocate and provide advice to the Interministerial Implementation Steering Committee on sustainability mechanisms until the end of the Strategy;

- **Roundtable on Future Planning** – to develop an integrated framework for future planning related to the impact of ADRD on government programs, communities and families. The Roundtable will:

    - build inter-sectoral relationships;
    - develop partnerships among a wide spectrum of community of interests;
    - bridge gaps between consumers and service providers; and
    - foster an environment of collaboration with a view to promoting public awareness of dementia and its relationship to healthy aging.

- **Provincial Alzheimer Group** – a community-led, ministry supported forum to build on the gains from the Alzheimer Strategy and continue to promote system change focusing on the needs of people with ADRD. The purpose of this Group is to:

    - provide support, co-ordination and overall direction to the components of the Strategy that are continuing forward;
    - ensure that the focus of the elements of the Strategy remains on improving service and making life more meaningful for those experiencing ADRD;
    - promote systemic change to support the needs of the growing population affected by ADRD;
    - foster and support linkages between consumers, providers, organizations, and policy makers; and
    - identify opportunities and models for future development of services, education, research and supportive of public policy.

In addition to these supports, a proposal for the **Alzheimer Knowledge Exchange (AKE)** was submitted to government. The AKE is a proposed vehicle to provide support and coordination, to sustain, advance and integrate the initiatives and thus maximize the Alzheimer Strategy investment. The proposed AKE consists of: a clearinghouse/resource centre; an interactive exchange; support for change champions and end users; and supports to move innovations in practice forward.

Final Comment

The results from the overall Alzheimer Strategy evaluation indicate that the Strategy was a success. The lessons learned from: the Strategy and its initiatives; how the Strategy was developed and implemented; and the issues related to sustainability will be of value to others who are considering the development of other strategies.

1.0 BACKGROUND

1.1 History and Overview of Ontario's Alzheimer Strategy

In 1999, the government announced Ontario's Strategy for Alzheimer Disease and Related Dementias (ADRD). The Strategy was the first comprehensive strategy on Alzheimer Disease in Canada with a total of $68.4 million invested between 1999 and 2004. The Strategy included ten specific but related initiatives aimed at improving the quality of life of people with ADRD and their caregivers in Ontario. The initiatives involved:

- education for health care providers, caregivers and the public;
- service enhancements and expansion; and
- research activities and knowledge exchange.

The specific initiatives and their respective goals are outlined in Table 1.

Table 1: Overview of the Alzheimer Strategy Initiatives and Initiative Goals

Initiative	Main Goal(s) *
#1: Staff Education & Training	- to offer annual training programs to staff of long-term care homes, community care access centres, and community support services serving people with ADRD - to assess additional training approaches - to evaluate training on an ongoing basis and ensure linkages between all educational components
#2: Physician Training	- to provide training to family physicians to assist them in the early detection and diagnosis of ADRD, optimal prescribing practices, and how best to use community services
#3: Increase in Public Awareness, Information and Education	- to raise awareness of ADRD, recruit volunteers, develop and facilitate caregiver support groups, and coordinate training events across the province
#4: Planning for Appropriate, Safe and Secure Environments	- to hold annual conferences over the course of the Strategy which explore the creative and functional design of living space for people with ADRD, as well as optimal models of care and appropriate improvements in home environments
#5: Respite Services for Caregivers	- to create new Alzheimer day program spaces and expand Alzheimer volunteer respite programs through ongoing provincial funding
#6: Research on Caregiver Needs	- to undertake research to determine what key community support services are needed by caregivers in Ontario
#7: Advance Directives on Care Choices	- to undertake broad consultation with key stakeholders on a provincial strategy on advance directives for care - to produce educational materials and provide appropriate training to ensure consistency in the Strategy's application - to pursue private and public partnerships for the development and dissemination of educational materials
#8: Psychogeriatric Consulting Resources	- to employ 50 psychogeriatric consultants to advise staff in long-term care homes and community service agencies on how to work with people who have dementia, other complex mental health needs and associated behaviours
#9A: Dementia Networks	- to improve the system of care required by persons, families and caregivers living with dementia through the creation of new sustainable networks or the maintenance of existing dementia networks
#9B: Research Coalition	- to explore the creation of a research coalition with a mandate to plan, coordinate and monitor collaborative, multidisciplinary Alzheimer research projects - the research coalition will promote Alzheimer research and be a resource to government in an advisory capacity

#9C: Specialized Geriatric Services	- to initiate a collaborative effort to refine the scope and mandate of specialized geriatric services to make their expertise more readily available to people with Alzheimer Disease and their families
#10: Intergenerational Volunteer Initiative	- to provide funding to support the recruitment, training and support of students in grades 11 and 12 who volunteer with individuals with ADRD at long-term care homes and community agencies

* Taken from *Ontario's Strategy for Alzheimer Disease and Related Dementias 1999 – 2004 Implementation Milestones and Status, April 2004* document.

1.2 Implementation Process and Structures

The Strategy was a joint initiative between the Ministry of Health and Long-Term Care (MOHLTC) and the Ontario Seniors' Secretariat (OSS), part of the Ministry of Citizenship and Immigration. A number of structures were established to oversee the implementation of the Strategy. These included the: Interministerial Implementation Steering Committee, External Advisory Committee and Initiative Working Groups and Committees. Each is described below.

1.2.1 Interministerial Implementation Steering Committee

The goal of the Interministerial Implementation Steering Committee was to ensure that the ten initiatives within the Alzheimer Strategy were implemented in a coordinated and timely fashion, consistent with government priorities, policies and processes. They provided direction to initiative-specific work groups and sought and considered advice from the External Advisory Committee. The committee also oversaw the evaluation of the Alzheimer Strategy.

The Interministerial Implementation Steering Committee was comprised of staff from the MOHLTC and OSS who were involved in the implementation of the Alzheimer Strategy. The co-leads responsible for the coordinated implementation of the ten initiatives were Elizabeth Esteves, Manager, Policy Initiatives, OSS and Michael Klejman, Regional Director, Central East Region, MOHLTC.

1.2.2 External Advisory Committee

The Advisory Committee was established in March 2000 and comprised opinion leaders in their respective fields, reflecting a balance of professional, consumer and geographic diversity. (See Appendix for a list of the Advisory Committee members.)

The goals of the External Advisory Committee were to:

- advise government on the implementation of the Alzheimer Strategy and ensure linkages across the ten initiatives;
- foster collaboration and partnerships across provider and consumer sectors; and
- help raise awareness of the implementation of the Strategy.

1.2.3 Initiative Representative Work Group

In June 2002, the Initiative Representative Work Group was established. The group consisted of representatives from each of the initiatives. The goal of the Initiative Representative Work Group was to ensure linkages were being made across initiatives. Specifically, they:

- oversaw the promotion, coordination and integration of the ten initiatives under the Alzheimer Strategy for the remainder of the Strategy and
- identified, advocated and provided advice to the Interministerial Implementation Steering Committee on possible ways of ensuring linkages across the ten initiatives.

Summary reports on the progress of the linkages across initiatives were delivered to the Advisory Committee.

The Initiative Representative Work Group also provided advice to the Evaluator on the stakeholder interviews, part of the overall Strategy evaluation.

1.2.4 Initiative Working Groups and Committees

For each of the initiatives, a Working Group or Committee was established to oversee the implementation of that specific initiative. These Working Groups and Committees were comprised of individuals with various areas of expertise, representing relevant associations and/or professions from areas across the province. Working Groups or Committees were established for the following initiatives: Initiative 1: Staff Education and Training; Initiative 2: Physician Training; Initiative 4: Planning for Appropriate, Safe and Secure Environments; Initiative 7: Advance Directives on Care Choices; Initiative 9A: Dementia Networks; Initiative #9B: Research Coalition; and Initiative 10: Intergenerational Volunteer Initiative.

A Regional Work Group, consisting of representatives from each of the seven regional MOHLTC offices, was also established. These representatives served as the leads for the Alzheimer Strategy within their respective Regional Offices. The Regional Work Group was responsible for overseeing the implementation of Initiatives 3, 5 and 8. They were also apprised of the developments and accomplishments within the other initiatives and provided advice on these initiatives as required.

The Working Groups and Committees for Initiatives #1, #2, #4, #7, #9A, and #9B as well as the Regional Work Group provided input into the development and implementation of the initiative-specific evaluations.

2.0 THE EVALUATION OF ONTARIO'S ALZHEIMER STRATEGY

2.1 Evaluation Overview and Approach

An independent Evaluator was hired to evaluate the overall Alzheimer Strategy and each of its initiatives. The Evaluator used an initial evaluation framework developed by the MOHLTC in consultation with a stakeholder group, as the basis for the evaluation. Evaluation activities began in 2001 with the Evaluator developing specific evaluation plans in collaboration with individual initiative Working Groups. Since some initiatives were still in the planning stages as of 2001, the evaluation evolved as these initiatives evolved.

The evaluation focused, as much as possible, on outcomes. As well, with many of the initiatives a multi-pronged evaluation approach was taken; that is, the Evaluator used multiple means of assessing the impact of various initiatives. Because of limitations in the methodologies that could be employed (due to budget and time constraints), this multi-pronged approach helped to increase the confidence in the results.

2.2 Purpose of this Report

The goal of this report is to provide a summary of the results from the overall Alzheimer Strategy evaluation. Where appropriate, trends and highlights from individual initiative evaluations will be shared and feedback presented on the process undertaken in implementing the Strategy. Section 3.0 provides an overview of the evaluation activities undertaken within each of the individual initiatives and the corresponding evaluation reports.

2.3 Methodology

As part of the initial development of the Alzheimer Strategy and through the work of the External Advisory Committee, four overall goals of the Alzheimer Strategy were identified. These were:

1. to support and improve the quality of life of people with ADRD and their caregivers;
2. to improve treatment, care and environmental conditions of people with ADRD;
3. to increase public awareness of dementia and the services available; and
4. to develop linkages between the initiatives within the Strategy.

It was these goals upon which the success of the Strategy was evaluated.

Data from the overall Alzheimer Strategy evaluation came primarily from interviews with stakeholders. Two sets of stakeholder interviews were conducted – the first in winter 2003 and the second in summer 2004. The Evaluator worked collaboratively with the Initiative Representatives Work Group to develop the interview schedule and identify the stakeholders to be interviewed. The interview schedule included questions about: the impact of the Strategy (as well as anticipated benefits over the next 3-5 years); major strengths of the Strategy and areas for improvement; the impact of the Strategy on linkages and collaborations within the system of care; and the impact of the Strategy on members/constituents of stakeholder associations/organizations. The stakeholders asked to participate in the interviews included representatives from associations, advocacy groups, and service provider groups.

The methodology used in conducting the stakeholder interviews is described in the two evaluation reports (*Assessing the Impact of Ontario's Strategy for Alzheimer Disease and Related Dementias –Summary of Stakeholder Interviews Interim Report and Final Report*). A total of 14 stakeholder groups were asked to participate in the first set of stakeholder interviews; 11 groups were asked to participate in the second set of interviews. For each set of interviews, all of the stakeholders agreed to participate.

Findings from both reports were similar. Results in this report are, therefore, based primarily on the final report of the stakeholder interviews since these interviews were conducted after the end of the Strategy. However, where appropriate, reference is made to results from the interim stakeholder interview report.

2.4 Results

2.4.1 To Support and Improve the Quality of Life of People with ADRD and their Caregivers

While the primary goal of the Alzheimer Strategy was to improve quality of life, there are two main challenges in trying to evaluate this goal. The first relates to the definition and measurement of quality of life. Quality of life is an elusive concept. Depending on the context in which it has been used, how it has been defined and assessed varies[1]. Much of the recent research involving quality of life has some basis in the work by Lawton who proposed a conceptual framework for quality of life for older adults. According to this framework, there are four domains that are of importance to quality of life: behavioural competence, psychological well-being, the objective environment, and one's perceived quality of life[2]. There has been some consensus among researchers in terms of certain aspects of the measurement of quality of life[1], however, much work still needs to be done.

The second challenge relates to the fact that the initiatives that comprised the Strategy did not target quality of life of people with dementia and their caregivers directly, but instead focused on factors believed to effect quality of life. When considered on either an individual initiative basis or as a collective, there was an assumption that positive effects resulting from the Strategy (e.g., the education of health care providers, enhancements to services, new knowledge gained from research) would lead to improvements in quality of life. While this assumption appears reasonable, it is difficult, if not impossible, to attribute any changes in quality of life directly to the Alzheimer Strategy.

Given these challenges, determining whether or not this goal had been met had to be done by making the assumption that positive impacts resulting from the Strategy would positively influence the quality of life of people with ADRD and/or their caregivers. In fact, the need to make this assumption was recognized by some of the individuals interviewed as part of the stakeholder interviews.

The perception among the majority of stakeholders was that the Strategy did have a positive effect on the quality of life of people with dementia and their caregivers. Sixty-four percent of the stakeholders interviewed (7 out of 11) rated the success of the Strategy in terms of supporting and improving quality of life as "very good" and 1 respondent rated it as "excellent". None of the respondents rated the success of the Strategy in this area as "poor" or "fair". (Ratings were made on a 5-point scale ranging from "poor" to "excellent".) The staff education initiative and the roles of the PRC and PEC were identified as the components of the Strategy that contributed most significantly to improving quality of life.

2.4.2 To Improve Treatment, Care and Environmental Conditions of People with ADRD

When the stakeholders were asked to rate the success of the Strategy in terms of improving treatment, care and environmental conditions of people with ADRD, over half rated the Strategy as "good", 18% rated it as "very good" and another 18% as "excellent". There was agreement among the stakeholders that improvements had been made in terms of treatment and care, but that progress on the environmental conditions of people with ADRD lagged behind. (Ratings were made on a 5-point scale ranging from "poor" to "excellent".)

The staff education initiative (particularly the P.I.E.C.E.S. learning initiative) and the PRCs were identified as instrumental to these improvements. The findings from the stakeholder interviews are further supported by results from the individual initiative evaluations. Specifically, in a survey of all long-term care homes in Ontario conducted in spring 2003 (response rate of 79%), 85% of respondents reported having at least one person actively serving as an In-house Psychogeriatric Resource Person as a result of the P.I.E.C.E.S. learning initiative. Further, these individuals were involved in various activities related to: the assessment and management of residents with challenging behaviours; working collaboratively with external resources; and coaching other staff to help them develop the P.I.E.C.E.S. competencies. In this same survey of long-term care homes, 83% of respondents reported that their staff had been in contact with the local PRC and the majority were "satisfied" or "very satisfied" with the type of assistance that the PRCs were able to provide.

2.4.3 To Increase Public Awareness of ADRD and the Services Available

In the stakeholder interviews, 46% of the respondents reported the success of the Strategy in terms of increasing public awareness of dementia and the services available as "very good" and 36% reported it as "excellent". Two participants did not provide a rating, indicating that they did not know the impact on public awareness. (Ratings were made on a 5-point scale ranging from "poor" to "excellent".) While the ratings of the success of the Strategy in this area were high, some stakeholders were not certain that overall increased public awareness could be attributed solely to the Alzheimer Strategy.

The PECs were identified as key to increasing awareness of dementia and the services available. Other components of the Strategy were also identified as important to public awareness, specifically, the staff education initiative, the PRCs the physician education initiative, and the Advance Care Planning education sessions conducted as part of Initiative #7.

In terms of other supporting evidence, in a survey of PECs and Alzheimer Chapter Executive Directors, increases in the amount of time dedicated to public awareness activities and other educational activities were also reported.

2.4.4 To Develop Linkages between the Initiatives within the Strategy

An important goal of the Alzheimer Strategy identified by the External Advisory Committee was that the initiatives within the Strategy not evolve in isolation. The Advisory Committee strongly promoted the sharing of information and resources between initiatives. In fact, one of the primary reasons for establishing the Initiative Representatives Work Group was to ensure that there were such linkages.

Over the course of the Strategy, numerous linkages were forged. Figure 1 provides an overview of the linkages between initiatives; details about these linkages are described afterwards.

The fewest number of linkages occurred with the three research initiatives - #4 (Planning for Appropriate, Safe and Secure Environments), #6 (Research on Caregiver Needs) and #9B (Research Coalition). The challenges associated with establishing the Research Coalition likely inhibited the ability to forge such linkages.

Figure 1: Overview of the Linkages between the Alzheimer Strategy Initiatives

Initiative

Initiative

	1	2	3	4	5	6	7	8	9A	9B	9C	10
1		X	X		X		X	X	X			
2	X		X				X	X	X		X	
3	X	X		X	X	X	X	X	X			X
4			X					X				
5	X		X					X				
6			X							X		
7	X	X	X									
8	X	X	X	X	X				X	X		
9A	X	X	X					X			X	
9B						X		X				
9C		X							X			
10			X									

Initiative 1: Staff Education and Training
- #2 – P.I.E.C.E.S. material were shared with Curriculum Advisory Committee and Opinion Leaders
- #5 – Adult Day Program (ADP) staff participated in educational activities; pilot project undertaken involving the implementation of the Enhancing Care Program in ADPs
- #7 – ACP training provided to services providers
- #8 – PRCs served as members of the P.I.E.C.E.S. and U-First! Educator Teams
- #9A – Dementia Networks promote education opportunities available through Initiative #1

Initiative 2: Physician Training
- #1 – P.I.E.C.E.S. material shared with Curriculum Advisory Committee and Opinion Leaders
- #3 – PECs helped to promote Peer Presenter activities
- #7 – Advance Care Planning education sessions conducted with physicians; materials developed as part of Initiative #7 shared with these physicians as well as the Opinion Leaders
- #8 – Contact information and information on PRC role shared with Opinion Leaders
- #9A – Opinion Leaders encouraged to participate in local Dementia Networks
- #9C – geriatricians and geriatric psychiatrists served as mentors for the Opinion Leader Program

Initiative 3: Increase in Public Awareness, Information and Education
- #1 –PECs involved in Dementia Studies education activities; PECs served as members of U-First! Educator Team
- #2 – PECs helped to promote Peer Presenter activities
- #4 – PECs participated in the conferences and have incorporated new learning
- #5 – PECs participated in the Enhancing Care pilot project in ADPs
- #6 – PECs helped identify potential participants for the Caregiver Needs survey
- #7 – PECs were involved as members of the Advance Care Planning Resource Teams
- #8 – PRCs and PECs often worked collaboratively to ensure that educational needs in their community were being met
- #9A – PECs participated in Dementia Networks
- #10 – PECs provided education to those who participated in the Intergenerational Volunteer initiative

Initiative 4: Planning for Appropriate, Safe and Secure Environments
- #3 – PECs participated in the conferences and have incorporated new learning
- #8 – PRCs participated in the conferences and have incorporated new learning

Initiative 5: Respite Services for Caregivers
- #1 – ADP staff participated in educational activities
- #3 – PECs participated in the Enhancing Care pilot project in ADPs
- #8 – Education for Adult Day Program staff was part of the mandate of the PRCs

Initiative 6: Research on Caregiver Needs
- #3 – PECs helped identify potential participants for the Caregiver Needs survey
- #9B – Research Coalition Working Group provided advice on Initiative #6

Initiative 7: Advance Directives on Care Choices
- #1 – ACP training provided to services providers
- #2 – Advance Care Planning education sessions conducted with physicians; materials developed as part of Initiative #7 shared with these physicians as well as the Opinion Leaders
- #3 – PECs were involved as members of the Advance Care Planning Resource Teams

Initiative 8: Psychogeriatric Consulting Resources
- #1 – PRCs served as members of the P.I.E.C.E.S. and U-First! Educator Teams
- #2 – Contact information and information on PRC role shared with Opinion Leaders
- #3 – PRCs and PECs often worked collaboratively to ensure that educational needs in their community were being met
- #4 – PRCs participated in the conferences and have incorporated new learning
- #5 – Education for Adult Day Program staff was part of the mandate of the PRCs
- #9A – Part of the PRC mandate was to support the development of Dementia Networks
- #9B – PRCs are members of the Research Coalition

Initiative 9A: Dementia Networks
- #1 – Dementia Networks promote education opportunities available through Initiative #1
- #2 – Opinion Leaders encouraged to participate in local Dementia Networks
- #3 – PECs participate in Dementia Networks
- #8 – Part of the PRC mandate was to support the development of Dementia Networks
- #9C – geriatricians and geriatric psychiatrists participate in local Dementia Networks

Initiative 9B: Research Coalition
- #6 – Research Coalition Working Group provided advice on Initiative #6
- #8 – PRCs are members of the Research Coalition

Initiative 9C: Specialized Geriatric Services
- #2 – geriatricians and geriatric psychiatrists served as mentors for the Opinion Leader Program
- #9A – geriatricians and geriatric psychiatrists participate in local Dementia Networks

Initiative 10: Intergenerational Volunteer Initiative
- #3 – PECs provided education to those who participated in the Intergenerational Volunteer initiative

2.4.5 Linkages and Collaborations within the System of Care

While the development of linkages and collaborations within the system of care (i.e., between service providers, educators, researchers, policy makers, agencies, organizations, advocacy groups, and/or networks) was not an anticipated goal of the Strategy, many of the stakeholders interviewed reported that this was one of the Strategy's greatest strengths. These linkages were reported to have had many benefits including:

- the bringing together of people who otherwise would not have collaborated to discuss how dementia care could be improved and what partnerships could be forged to plan services;
- increased dialogue and communication across the continuum of care;
- development of a common vision, language, and approach across the community of service providers;
- reduced duplication of services because of increased awareness of the array of services available;
- increased collaboration between those that disseminate new knowledge and those that use it;
- reduced animosity, suspicion, and lack of trust as well as being less territorial among provider groups and between provider groups and advocacy groups;
- reduced silo thinking at all levels;
- greater feelings of support among service providers; and
- increased collaboration between service providers and caregivers in terms of planning and coordination.

2.4.6 Overall Evaluation of the Success of the Alzheimer Strategy

While the stakeholders identified some limitations and areas for improvement (discussed below) the evidence from the Alzheimer Strategy evaluation indicates that the Strategy's four primary goals were met. There were improvements in quality of life, treatment, and care for people with ADRD, there was greater public awareness of ADRD and the services available, and there were numerous linkages forged between the initiatives within the Strategy. In addition, the Strategy led to various collaborations within the system of care, many of which would not likely have occurred without the Strategy. These collaborations were identified as one of the key strengths of the Strategy.

Success of the Alzheimer Strategy is also evident from the success of individual initiatives. In all cases, the overall goal of each initiative was achieved. (The initiative-specific goals are outlined in Table 1 on page 6.) It is recognized, however, that while the goals of each initiative were met, some stakeholders had hoped that the outcomes of certain initiatives would extend beyond the initial goals (e.g., Initiative #9C – Specialized Geriatric Services).

2.4.7 Limitations / Areas for Improvement

In addition to the many benefits attributed to the Strategy, some limitations and areas for improvement were also identified.

The primary concern raised in relation to the Alzheimer Strategy was that of sustainability. The majority of stakeholders interviewed were concerned that the many benefits realized as a result of the Strategy would not be maintained and supported. The anticipated increase in the prevalence rate of ADRD was highlighted as a major reason for developing a concise sustainability plan.

Stakeholders identified the following as necessary for sustainability:

- continued support for specific initiatives, especially those aimed at improving information sharing and knowledge about ADRD, improving caregiving skills, and enhancing service delivery;
- a commonly agreed upon framework and vision for supporting ongoing activities;
- the integration of the achievements of the Strategy into daily practice (i.e., standards regarding the implementation of new knowledge into practice, organization support to ensure sustainability); and
- mechanisms for evaluation, research, and dissemination of new information.

In addition to the issue of sustainability, there were a handful of other limitations / areas for improvement identified by the stakeholders. Some of these related to the planning / implementation of the Strategy, specifically:

- underestimation of time required for planning prior to the roll-out of initiatives; this was particularly true for Initiative #2 - because of the length of time required for planning, implementation of the activities within this initiative did not begin until later in the Strategy;
- initiatives were implemented simultaneously but should have built on each other (e.g., research on caregiver needs should have informed the allocation of resources to respite services);
- lack of participation of sectors that were not receiving funding from the MOHLTC (e.g., retirement homes); and
- limited participation in educational activities by staff in the acute care system, particularly emergency room workers.

Other limitations / areas for improvement related to specific initiatives:

- Initiative #4 – conferences may not have been the best means of making improvements to the environmental conditions of people with ADRD;
- Initiative #5 – need for more flexible respite options (e.g., in-home respite);
- Initiative #9B – the Research Coalition has not moved forward as quickly as it should have to build a stronger and competitive position for research in Ontario; and
- Initiative #9C – lack of action in response to the recommendations on Specialized Geriatric Services.

Other important limitations / areas for improvement included:

- disproportional distribution of PECs across the province and
- limited funding in the long-term care system to implement specific initiatives (e.g., implementation of new care approaches, environmental redesign).

2.5 Comment on the Evaluation of the Alzheimer Strategy

There were many positive aspects to the Alzheimer Strategy evaluation. First and foremost was the government's commitment to having the Alzheimer Strategy evaluated. The evaluation was an important component of the Strategy and was not considered as an afterthought. An independent Evaluator was hired near the beginning of the Strategy and a significant amount of funds were set aside for evaluation activities. Second, the evaluation focused on outcomes as much as possible. Outputs (e.g., the number of people trained, the number of activities undertaken) are sometimes the desired result of an evaluation, but their value is limited. A focus on outcomes (i.e., the impact of the initiatives) is more meaningful and can speak to the value of particular activities. Third, the Evaluator worked collaboratively with the government, various Working Groups and those involved in the Strategy initiatives to design and implement evaluation plans for each initiative and the Strategy overall. These efforts allowed for evaluation activities and results that were relevant and meaningful. Fourth, as much as possible a multi-pronged evaluation approach was used (i.e., multiple methods were used to assess the impact of the initiatives). For example, the evaluation of Initiative #8 (Psychogeriatric Resource Consultants) involved gathering: units of service data; feedback from the PRCs, their sponsoring / partner agencies, and outreach teams; feedback from long-term care homes across the province (a primary target of the PRCs' activities); and feedback from recipients of the PRCs' service. This type of approach enables one to be more confident that the results reflect the true impact of the initiative.

While there were many advantages of the Alzheimer Strategy evaluation, it was also subject to some limitations / areas for improvement.

In terms of the evaluation design, because the Alzheimer Strategy initiatives were implemented province-wide and funding - while significant - was limited, control groups could not be used to evaluate the impact of the initiatives. Instead, pre-post designs were typically implemented, limiting the ability to attribute changes directly to the Alzheimer Strategy.

Another limitation was the challenge involved in measuring and evaluating the impact of the Alzheimer Strategy on quality of life (discussed above). While this was the ultimate goal of the Strategy, the Strategy was designed to effect factors likely associated with quality of life (e.g., increase knowledge of service providers and caregivers). The evaluation could examine whether the Strategy had an effect on these factors, but could only assume that changes in these areas would, in turn, positively influence quality of life. Related to this was the challenge of evaluating the impact of certain initiatives on those with ADRD. In a few cases this was possible (e.g., in the P.I.E.C.E.S. evaluation, some assessment of the impact of the training on long-term care residents was possible; as part of the evaluation of Initiative #3, feedback from people with ADRD was obtained on the PECs' educational activities). However, in most cases this was not feasible and, thus, one must assume that the positive effects of the Strategy ultimately influenced the lives of those with ADRD and/or their caregivers.

The Evaluator worked collaboratively with those involved with each of the initiatives to plan and implement the evaluation activities. However, at times it was challenging to get buy-in regarding the importance of the evaluation from all involved. For some of these individuals, service was their priority and the evaluation was considered extra work. A related challenge involved ensuring that the evaluation activities were implemented in a consistent manner. In a few cases, the evaluation required using participants in certain initiatives to implement the evaluation activities (e.g., to administer questionnaires). While all efforts were made to ensure that such activities were as straightforward and effortless as possible, in a small percent of cases challenges existed (e.g., use of the wrong questionnaire).

Working with stakeholders could also have its challenges. Because the Strategy involved multiple stakeholder groups, their hopes about what would be achieved as a result of the Strategy sometimes differed. As a result it was not always possible to satisfy all groups.

Another challenge related to the sharing of evaluation results. Because of the time required to analyze and report on the data, results were not always available to inform future activities. This became a greater challenge as the number of activities to evaluate increased.

A final challenge was the limited ability to conduct long-term follow-ups of the Strategy activities. Longer-term follow-ups would allow for a fuller understanding of the impact of the initiatives.

2.6 Comment on the Implementation of the Alzheimer Strategy

In the stakeholder interviews, many stakeholders commented on the implementation of the Alzheimer Strategy, praising the planning process as well as its implementation. The following provides a summary of the strengths identified.

Strengths related to the Planning of the Alzheimer Strategy:

- the government undertook a rational, comprehensive planning process;
- ongoing consultation with key stakeholders;
- strong political leaders who backed the Strategy;
- the interministerial approach helped to ensure that there was a sense of common purpose and direction and a pooling of resources;
- the comprehensiveness of the Strategy was key (i.e., including service, education and research); it tackled a multifaceted problem on a number of fronts;
- building the Strategy on existing sectors and supports;
- having focused and clear goals;
- interdisciplinary nature of the Strategy – it has brought together players around the table who had not been together before; and
- importance given to the evaluation of the Strategy; involving the Evaluator in the planning process.

Strengths related to the Implementation of the Alzheimer Strategy:

- dedication of resources, both human and financial, to implement the Strategy initiatives;
- multi-level linkages: from provincial to regional to the local level;
- the recognition of the important role that family members play and the need to provide support to this important resource to ensure that it is appropriate and effective;
- a proactive approach in building a strong educational support structure and strengthening of support services in preparation for the anticipated increase in prevalence of dementia;
- development and implementation of specific initiatives:
    - #8 - PRCs
    - #1 - P.I.E.C.E.S. and U-First initiatives and related resource material to support staff in LTC homes and community agencies
    - #2 – commitment to physician education
    - #3 – PECs
    - #9A - Dementia Networks;
- dedication of the individuals that have been involved in the Strategy;
- ability to adapt initiatives at the local level, recognizing the needs of various communities;
- the Strategy brought together all stakeholders in a team effort, rather than in a competitive environment resulting in open dialogue; and
- shared vision and commitment contributed to perseverance despite challenges.

Areas for improvement related to the implementation of the Alzheimer Strategy have already been outlined (see Section 2.4.7).

2.7 Comment on Sustainability Efforts

As previously mentioned, the issue of sustainability was of significant importance to the External Advisory Committee. Because of their desire to ensure that the gains from the Strategy could be sustained, the Advisory Committee established a subgroup to examine sustainability and linkages between the Strategy initiatives.

A draft plan for the sustainability of the Alzheimer Strategy was endorsed by the Advisory Committee in December 2002. The plan recommended that certain supports be in place at the end of the Strategy's implementation period (i.e., March 31, 2004) to ensure that the benefits realized as a result of the Strategy would continue and expand. These supports included:

- **Initiative Representative Work Group** (described above) – the role of this group was to oversee the promotion, coordination and integration of the Alzheimer Strategy initiatives and to identify, advocate and provide advice to the Interministerial Implementation Steering Committee on sustainability mechanisms until the end of the Strategy;

- **Roundtable on Future Planning** – to develop an integrated framework for future planning related to the impact of ADRD on government programs, communities and families. The Roundtable will:

    - build inter-sectoral relationships;
    - develop partnerships among a wide spectrum of community of interests;
    - bridge gaps between consumers and service providers; and
    - foster an environment of collaboration with a view to promoting public awareness of dementia and its relationship to healthy aging.

- **Provincial Alzheimer Group** – a community-led, ministry supported forum to build on the gains from the Alzheimer Strategy and continue to promote system change focusing on the needs of people with ADRD. The purpose of this Group is to:

    - provide support, co-ordination and overall direction to the components of the Strategy that are continuing forward;
    - ensure that the focus of the elements of the Strategy remains on improving service and making life more meaningful for those experiencing ADRD;
    - promote systemic change to support the needs of the growing population affected by ADRD;
    - foster and support linkages between consumers, providers, organizations, and policy makers; and
    - identify opportunities and models for future development of services, education, research and supportive of public policy.

In addition to these supports, a proposal for the **Alzheimer Knowledge Exchange (AKE)** was submitted to government. The AKE is a proposed vehicle to provide support and coordination, sustain, advance and integrate the initiatives and thus maximize the Alzheimer Strategy investment. The proposed AKE consists of: a clearinghouse/resource centre; an interactive exchange; support for change champions and end users; and supports to move innovations in practice forward.

2.8 Concluding Comments

The four overall goals used to assess the success of the Alzheimer Strategy were:

1. to support and improve the quality of life of people with ADRD and their caregivers;
2. to improve treatment, care and environmental conditions of people with ADRD;
3. to increase public awareness of dementia and the services available; and
4. to develop linkages between the initiatives within the Strategy.

Data from the overall Strategy evaluation and the initiative specific evaluations indicated that these four goals had been met. Participants in the overall evaluation reported that the Strategy contributed to improvements in quality of life and treatment and care for people with ADRD, as well as greater public awareness of ADRD and the services available. They also reported that numerous linkages among the Strategy initiatives had been forged.

In addition to these goals, the Strategy led to various collaborations within the system of care that resulted in benefits for people with ADRD and their caregivers, service providers and organizations, advocacy groups, and the care system. These collaborations were identified as one of the key strengths of the Strategy.

Some limitations and/or areas for improvement related to the Strategy were also identified. These included: issues related to the planning and implementation of the Strategy, shortcomings of certain Strategy initiatives, and other limitations related to funding and resource allocation.

The primary concern raised in relation to the Alzheimer Strategy was that of sustainability. The majority of stakeholders interviewed regarding the impact of the overall Strategy were concerned that the many benefits realized as a result of the Strategy would not be maintained and supported.

Stakeholders identified the following as necessary for sustainability:

- continued support for specific initiatives, especially those aimed at improving information sharing and knowledge about ADRD, improving caregiving skills, and enhancing service delivery;
- a commonly agreed upon framework and vision for supporting ongoing activities;
- the integration of the achievements of the Strategy into daily practice (i.e., standards regarding the implementation of new knowledge into practice, organizational support to ensure sustainability); and
- mechanisms for evaluation, research, and the dissemination of new information.

The results from the overall Alzheimer Strategy evaluation indicate that the Strategy was a success. The lessons learned from: the Strategy and its initiatives; how the Strategy was developed and implemented; and the issues related to sustainability will be of value to others who are considering the development of other strategies.

3.0 SUMMARY OF EVALUATION ACTIVITIES AND REPORTS

The following provides an overview of the evaluation activities undertaken and the corresponding evaluation reports. If you have any inquires about these reports please contact:

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Alzheimer Strategy – Overall Evaluation

Methodology Employed	Evaluation Report(s)
▪ Interviews with key stakeholder associations / organizations – Phase I and II ▪ The interviews focused on the impact of the Alzheimer Strategy, strengths, weaknesses, etc.	▪ Stakeholder Interviews Interim Report Aug03 ▪ Stakeholder Interviews Final Report Nov04

Initiative 1: Staff Education and Training

Component	Methodology Employed	Evaluation Report(s)
Putting the P.I.E.C.E.S. Together Learning Initiative	▪ Pre, immediate post and post questionnaires (confidence questions, feedback on sessions, how knowledge will be used) ▪ Survey of LTC homes (feedback on the P.I.E.C.E.S. Initiative and the PRC Role) ▪ Interviews with LTC homes that had success and limited success with P.I.E.C.E.S.	▪ Init 1 - "Putting the P.I.E.C.E.S. Together" Training Initiative 2001 Final Evaluation Report ▪ Init 1 - "Putting the P.I.E.C.E.S. Together" Training Initiative 2002, Final Evaluation Report * ▪ Init 1 - Survey of Long-Term Care Facilities: Feedback on the P.I.E.C.E.S. Initiative ▪ Init 8 - Survey of LTC Facilities: Feedback on the PRC Role ▪ Putting the P.I.E.C.E.S. Together Training Initiative: Report on Follow-up Interviews, 2005
Enhancing Care in Adult Day Programs	▪ Pre and post questionnaires re: ECP ▪ Focus groups with ADP staff and clients/family members	▪ Init 1 - Implementing the Enhancing Care Program in ADPs: Final Evaluation Report
U-First! Program	▪ Pre, immediate post and follow-up questionnaires (confidence questions, feedback on sessions, how knowledge will be used)	▪ Init 1 - Evaluation of the U-First! Program: Final Report
Enabler Program	▪ Pre, immediate post and follow-up questionnaires (confidence questions, feedback on sessions, how knowledge will be used)	▪ Init 1 - Evaluation of the Enabler Program: Final Report
Community P.I.E.C.E.S.	▪ Pre, immediate post and follow-up questionnaires (confidence questions, feedback on sessions, how knowledge will be used)	▪ Init 1 - Evaluation of the Community P.I.E.C.E.S. Program: Final Report
Reimbursement for Education	▪ Feedback obtained after completion of course re: how knowledge will be used	▪ Init 1 - Reimbursement for Education Activities: Final Evaluation Report

* Evaluation conducted by aestima Research, not the Alzheimer Strategy Evaluator.

Initiative 2: Physician Training

Component	Methodology Employed	Evaluation Report(s)
Opinion Leader Program	▪ Pre questionnaire and 3 follow-up questionnaires (knowledge, dementia practices, mentoring relationship, opinion leader activities) ▪ Questionnaires to obtain feedback on workshops ▪ Opinion Leader and mentor logs ▪ Survey of physicians who were identified as being influenced by Opinion Leaders	▪ Init 2 Final Evaluation Report 2006
Peer Presenter Program	▪ Questionnaires to obtain feedback on workshop ▪ Peer Presenter didactic sessions – questionnaire to obtain feedback on session ▪ Peer Presenter interactive sessions – pre, immediate post and follow-up questionnaires (understanding of topic area, feedback on session, how knowledge used)	
Family Medicine Preceptor Program	▪ Questionnaires to obtain feedback on workshops	
ACP Initiative	▪ Pre, immediate post and follow-up questionnaires (familiarity with ACP issues, confidence questions, feedback on sessions)	
Curriculum	▪ Summary of activities undertaken by the Curriculum Advisory Committee	

Initiative 3: Increase in Public Awareness, Information and Education

Methodology Employed	Evaluation Report(s)
▪ Collection of units of service data	▪ Init 3 Final Evaluation Report – Overview of Results
▪ Survey of PECs; survey of PECs and Alzheimer Chapter Executive Directors	
▪ Questionnaire to obtain feedback on educational activities	

* Note: Final reports on the individual components of the Initiative #3 evaluation have been shared with the PECs and the Alzheimer Chapters.

Initiative 4: Planning for Appropriate, Safe and Secure Environments

Methodology Employed	Evaluation Report(s)
▪ Focus group with selected conference participants	▪ Init 4 – Summary of Focus Group Results

Initiative 5: Respite Services for Caregivers

Methodology Employed	Evaluation Report(s)
▪ Survey of Adult Day Programs that received funding	▪ Init 5 – Final Evaluation Report

Initiative 6: Research on Caregiver Needs

Methodology Employed	Evaluation Report(s)
▪ Research undertaken on caregiver needs (literature review, survey, focus groups)	▪ Research Reports *
▪ Review of scope of activities undertaken	▪ Init 6 – Final Evaluation Report

* Reports prepared by Dr. Bryan Smale and Dr. Sherry Dupuis

Initiative 7: Advance Directives on Care Choices

Component	Methodology Employed	Evaluation Report(s)
Physician Opinion Leader Conferences	▪ Feedback on sessions	▪ Init 7 - Final Report on the Ian Anderson Sessions
ACP Resource Teams & Activities	▪ Pre and post questionnaires for Resource Team members ▪ Pre, immediate post and follow-up questionnaires for public education session participants ▪ Pre and immediate post questionnaires for service provider education session participants	▪ Init 7 – ACP Resource Teams Final Evaluation Report ▪ Init 7 – ACP Sessions for Members of the Public Final Evaluation Report ▪ Init 7 – ACP Sessions for Service Providers Final Evaluation Report
LTC Administrators	▪ Pre and immediate post questionnaires	▪ Init 7 - ACP Sessions for LTC Home Administrators Final Evaluation Report

Initiative 8: Psychogeriatric Consulting Resources

Methodology Employed	Evaluation Report(s)
▪ Collection of units of service data	▪ Init 8 Final Evaluation Report – Overview of Results
▪ Survey of LTC homes (feedback on the P.I.E.C.E.S. Initiative and the PRC Role)	
▪ Telephone interviews to obtain feedback on case-based activities	
▪ Questionnaire to obtain feedback on topic-specific educational activities	
▪ Questionnaires to obtain feedback from PRCs, PRC sponsoring/partner agencies, and Geriatric Mental Health Outreach Teams	

* Note: Final reports on the individual components of the Initiative #8 evaluation have been shared with the PRCs and their sponsoring and partner agencies.

Initiative 9A: Dementia Networks

Methodology Employed	Evaluation Report(s)
▪ Questionnaire to obtain feedback on regional sessions conducted about Dementia Networks	▪ Init 9A – Summary of Feedback on Regional Sessions
▪ Interviews and questionnaires to obtain feedback on Dementia Networks	▪ Init 9A – Evaluation Report Phase 1 – 2003 ▪ Init 9A – Evaluation Report Phase 2 – 2005

Initiative 9B: Research Coalition

Methodology Employed	Evaluation Report(s)
▪ Compilation of information on Research Coalition members ▪ Summary of activities undertaken by Research Coalition	▪ Init 9B – Research Coalition Final Evaluation Report

Initiative 9C: Specialized Geriatric Services

Methodology Employed	Evaluation Report(s)
▪ Summary of recommendations by expert panel	▪ Final Report *

* Report prepared by the Initiative #9C Consultants, not the Alzheimer Strategy Evaluator

Initiative 10: Intergenerational Volunteer Initiative

Methodology Employed	Evaluation Report(s)
▪ Summary of activities undertaken and the evaluation of these activities	▪ Final report * ▪ Booklet: Creating a Local Intergenerational Alzheimer Project**
▪ Comment on Consultant's report	▪ Init10 – Final Report by Alzheimer Strategy Evaluator

* Evaluation conducted by the Initiative Consultant, not the Alzheimer Strategy Evaluator.

** Booklet developed by the Older Adults Centres Association of Ontario, United Generations of Ontario, and the Alzheimer Society of Ontario.

4.0 APPENDIX – MEMBERSHIP OF THE EXTERNAL ADVISORY COMMITTEE

	Name	Address
1	Mark Mieto (Chair)	Chief Administrative Officer City of Greater Sudbury PO Box 5000, Station A Sudbury, ON P3A 5P3
2	Jim Armstrong	Chief Executive Officer Ontario Association of Community Care Access Centres (OACCAC) 1940 Eglinton Ave. East, Suite 500 Scarborough, ON M1L 4R1
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- External Advisory Committee
- Initiative Representatives Work Group
- Initiative #1 Work Group
- Initiative #2 Steering Committee and the Initiative #2 Evaluation Subcommittee
- Initiative #7 Work Group
- Initiative #9A Work Group and the Dementia Network Advisory Committee
- Initiative #9B Work Group
- MOHLTC Regional Work Group
- Alzheimer Society of Ontario
- P.I.E.C.E.S. Consultation Team
- PRCs and the PRC Evaluation Subcommittee
- PECs and Alzheimer Chapter Executive Directors

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7.0 GLOSSARY

Numerous acronyms were used in relation to the Alzheimer Strategy. The following provides definitions for these various acronyms.

ACP	Advance Care Planning
ADP	Adult Day Program
ADRD	Alzheimer Disease and related dementias
AKE	Alzheimer Knowledge Exchange
DN	Dementia Network
DNAC	Dementia Network Advisory Committee
LTC	Long-Term Care
MOHLTC	Ministry of Health and Long-Term Care
OL	Opinion Leader
OSS	Ontario Seniors' Secretariat
P.I.E.C.E.S.	Physical, Intellectual, Emotional, Capabilities, Environment, Social
PP	Peer Presenter
PRC	Psychogeriatric Resource Consultant
PRP	Psychogeriatric Resource Person
PEC	Public Education Coordinator