Assessing the Impact of Ontario's Strategy for Alzheimer Disease and Related Dementias

SUMMARY OF STAKEHOLDER INTERVIEWS: FINAL REPORT

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BACKGROUND

In 1999, the Ontario government announced a 5-year strategy for Alzheimer Disease and Related Dementias. As part of this, one of the government's commitments has been the evaluation of the overall Strategy and each of its initiatives. One component of this evaluation was qualitative interviews with key stakeholders. Interviews were conducted with representatives of various key stakeholder associations/organizations from across the province in order to gather information on what impact the Strategy has had, including the identification of some of its successes and areas requiring improvement. Two sets of interviews were conducted: the first in winter/spring 2003 and the second set in July 2004. This report provides a summary of the second set of stakeholder interviews. Findings from the first set of interviews are presented elsewhere.

METHODOLOGY

The interview questions were developed by the Evaluator in conjunction with members of the Initiative Representative Work Group, a subcommittee of the External Advisory Committee. The questions focused on: assessing the impact of the Strategy (as well as the anticipated benefits over the next 3-5 years) in a variety of areas (i.e., improving quality of life, improving treatment, care and environmental conditions, and increasing public awareness); the major strengths of the Alzheimer Strategy and areas requiring improvement; the impact of the Strategy on improving linkages and collaboration; and the Strategy's impact on the members / constituents within the stakeholder associations / organizations.

A total of 11 stakeholder groups were identified and each of these groups participated in the interviews. For the Dementia Networks, 7 networks were randomly selected to participate in the interviews (one network per MOHLTC region). A total of 17 individuals were interviewed for this evaluation. The average length of the interviews was 29 minutes (SD = 9.11; range of 13 to 45 minutes).

A list of the associations and organizations that contributed to these interviews is located in Appendix. A contact person from each stakeholder association / organization was sent a letter explaining the purpose of the interview and was provided with a copy of the questions to be asked. The contacts were informed that the purpose of the interview was to obtain an understanding of what impact the Strategy has had, if any, from the perspective of the members/constituents of their association/organization.

PRESENTATION OF RESULTS

For some questions, stakeholders were asked to rate certain aspects of the Strategy. For some stakeholder groups (e.g., Dementia Networks, Alzheimer Society of Ontario), more than one person was interviewed or contributed to the interview, thus, more than one rating was provided. In these cases, an average rating for the stakeholder association / organization was calculated, and this average value was used in calculating the overall rating (i.e., across all stakeholder groups).

Most of the questions asked as part of the stakeholder interviews were qualitative in nature. The purpose of the qualitative interviews was to describe the impact of the Alzheimer Strategy from the perspective of the key stakeholders. Qualitative data are not intended to be representative. Thus, the results presented in this report should not be generalized.

In presenting the results from the stakeholder interviews, the following guidelines were used to help summarize the information obtained:

- "a few stakeholders" = 1 – 2 stakeholders (~25% of the stakeholders)

- "some/several" stakeholders" = 3 – 5 stakeholders (~25% - 50% of the stakeholders)
- "many stakeholders" = 6 – 11 stakeholders (>50% of the stakeholders)

The statements that have been included (e.g., in the tables and boxes in Section 2) are not specific quotes, but points that summarize the information obtained for each particular question.

This report is divided into two sections. Section 1 summarizes the highlights or main themes that emerged from the interviews. Section 2 provides a more detailed summary of the responses to each question.

Caveat

The stakeholder interviews described in this report were conducted at one point in time (July 2004). Since these interviews were conducted, a number of post-strategy activities have been initiated. A summary of these activities is provided in Appendix B.

SECTION 1: HIGHLIGHTS EMERGING FROM THE STAKEHOLDER INTERVIEWS

Successes of the Alzheimer Strategy

Overall, stakeholders identified many benefits that had been realized as a result of the Alzheimer Strategy. While a few stakeholders indicated that there was a lack of objective data to attribute changes directly to the Strategy (e.g., increased public awareness), many were able to identify outcomes that they believed would not have occurred without the Strategy (e.g., increased and improved linkages and collaborations among service providers).

Supporting and improving quality of life of people with Alzheimer Disease and Related Dementias (ADRD) and their caregivers

- When asked to rate the success of the Strategy in terms of supporting and improving quality of life of people with ADRD and their caregivers, using a scale of 1 to 5 (1 = poor; 5 = excellent), 72.7% of the stakeholders rated the success of the Strategy as “very good” or “excellent” and another 27.3% rated it as “good”.

- The staff education initiative and the roles of the Psychogeriatric Resource Consultants (PRCs) and Public Education Coordinators (PECs) were identified as important to improving quality of life of people with ADRD and their caregivers.

- A few stakeholders commented that they had no objective way of measuring the impact of the Strategy on quality of life - there may have been improvements, but it was difficult to determine if these were directly because of the Strategy. Likewise, the full impact on quality of life is not known as some of the initiatives were still evolving.

- Most stakeholders identified benefits in terms of improving quality of life that would be realized over the next 3 to 5 years, particularly related to increased knowledge and skills of family, service providers’ ability to care for those with ADRD, and improved access to services.

- These benefits will be realized through continued education and collaboration among service providers. Stakeholders indicated that continued funding for educational initiatives and the Dementia Networks will be necessary to sustain benefits.

Improving treatment, care, and environmental conditions of people with ADRD

- When asked to rate the success of the Strategy in terms of improving treatment, care and environmental conditions on a scale of 1 to 5 (1 = poor; 5 = excellent), 36% of the stakeholders rated the success of the Strategy as “very good” or “excellent” and another 55% rated it as “good”.

- Overall, most stakeholders identified improvements in treatment and care, but indicated the changes to environmental conditions have lagged behind.

- Improvements to treatment and care were most often attributed to the staff education initiative and the PRC role.

- Although many stakeholders indicated that there have been profound changes in treatment and care for which benefits will continue to be realized, many did not think that there was sufficient attention paid to environmental conditions to realize or maintain change. Funding for the Dementia Networks, treatment-related research, and physician education were some of the resources identified as necessary to sustain benefits.

Increasing public awareness of dementia and the services available

- When asked to rate the success of the Strategy in terms of increasing public awareness of dementia and the services available on a scale of 1 to 5 (1 = poor; 5 = excellent), 46% of the stakeholders rated the success of the Strategy as "very good" and 36% rated it as "excellent".

- Education initiatives, particularly the PEC role and the Dementia Networks were identified as instrumental to increased public awareness about ADRD and the services that are available. A few stakeholders were not certain that overall increased public awareness of ADRD could be attributed directly, or solely, to the Alzheimer Strategy.

- Increased public awareness was identified by some stakeholders as the foundation for many of the changes realized as a result of the Strategy. Changes in attitudes towards dementia and dementia treatment, and improved awareness of available services were attributed to improved public awareness of ADRD.

- Despite increases in public awareness, many stakeholders indicated that more work is still needed to promote public awareness and accessibility to services. There continues to be limited access to services because of lack of awareness and understanding of dementia, stigma, social isolation, and withdrawal from services when providers lack knowledge and comfort with ADRD.

Linkages and collaboration within the system of care

- When asked to rate the success of the Strategy in terms of improving linkages and collaboration within the system of care on a scale of 1 to 5 (1 = poor; 5 = excellent), 81.8% of the stakeholders rated the success of the Strategy as "very good" or "excellent" and another 9.1% rated it as "good".

- There was general agreement that the Alzheimer Strategy has resulted in improved linkages and collaboration within the system of care – linkages that may not have occurred otherwise. These linkages increased dialogue and collaboration across the continuum of care to forge partnerships with the goal of improving services to, and care of, those with ADRD.

- Some stakeholders expressed concern about the sustainability of these linkages in the long-term and emphasized the need to continue to forge new linkages (e.g., with researchers).

- Stakeholders identified the need to develop communication structures and mechanisms to support exchange of information and to enhance and maintain established linkages.

Strengths and Limitations of the Strategy

- The Strategy has accomplished a tremendous amount in five years. The strategy was described as creative and innovative, primarily because of its multifaceted and multi-sector approach. Many stakeholders described the excitement and momentum created with the possibilities for change.

- Many strengths were identified:

  - The Strategy was well supported by top levels of government and developed multi-level linkages: from provincial to regional to the local level.

  - The consultation and implementation process was inclusive and comprehensive.

  - Education initiatives were identified as major strengths of the Strategy, in terms of their ability to empower individuals and organizations with knowledge and resources to improve dementia care.

  - The Dementia Networks were also identified as a key strength of the Strategy. The Networks have given various services/organizations a better sense of the continuum of services that are available and provided a vehicle for them to work collectively together toward a common goal of improving service availability and delivery.

- While the Strategy has had many important outcomes, stakeholders acknowledged that there continue to be areas that require improvement, including:

  - participation of acute care settings and sectors not receiving government funding (e.g., retirement homes)

  - integration of new knowledge into daily practice

  - incentives for change within the health system

  - utilization of staff training in some areas (e.g., P.I.E.C.E.S.)

  - continuation of physician training activities

  - community support for caregiver respite and in-home care

  - clear guidelines and support for Dementia Networks

  - ongoing support to help sustain what has been achieved through the Alzheimer Strategy (e.g., support to: attend educational activities, modify environments, coordinate Dementia Networks, specialized geriatric services)

  - identification of and bridging of gaps in the provision of geriatric services across the province; there is a need for a comprehensive policy and planning for geriatric services across the province

  - development of an overall vision and framework for sustainability of Strategy successes.

Sustainability of Successes

- Many stakeholders expressed concern about the sustainability of benefits with many indicating that the work of the Strategy over the past five years is only the beginning and more work needs to be done to build on and sustain achievements. The anticipated increase in the prevalence rate of ADRD was highlighted as a major reason for developing a concise sustainability plan.

- Although much excitement has been generated about dementia care and a common vision for improved dementia care has been forged, many believe that goodwill alone cannot sustain this vision. Ongoing support is needed to help sustain and build upon the gains that have been made.

- There is a need for more strategic planning for sustainability, such as the Roundtable and similar initiatives. Stakeholders indicated that the Roundtable framework should emphasize education and awareness, service delivery, caregiver support, and research and evaluation.

- Sustainability requires a commonly agreed upon framework and vision for supporting ongoing activities and mechanisms for evaluation, research, and dissemination of new information.

- Continued support for specific initiatives, especially those aimed at improving information sharing and knowledge about ADRD, improving caregiving skills, and enhancing service delivery were identified as critical to sustainability.

- Research and evaluation were identified as necessary to support and sustain elements of the Strategy initiatives.

- Seventy percent of the stakeholders interviewed attended the *Invitational Alzheimer Strategy Workshop: Coming Together to Shape the Future.* Generally, stakeholders commented that the successes of the Strategy will be sustained if major activities that were identified in the consultation as necessary to move the Strategy forward are supported, funded, and implemented. Concern was expressed that the workshop did not focus more on developing consensus on a sustainability plan and examining fundamental changes within the health care system needed to support sustainability; however, these are the roles of the Provincial Alzheimer Group and the Roundtable.

- There was an overriding belief that there is a need for the Roundtable and in particular the development of a framework guided by clear principles and objectives, and that occurs within the context of a broad plan for the care of the elderly. However, some stakeholders expressed concern about the lack of clarity around the objectives of the Roundtable.

SECTION 2: DETAILED SUMMARY OF RESPONSES FROM STAKEHOLDER INTERVIEWS

1. Overall, how would you rate the success of the Alzheimer Strategy in terms of supporting and improving the quality of life of people with dementia and their caregivers?

(N=11)

	Poor 1	Fair 2	Good 3	Very Good 4	Excellent 5	Mean (SD)
% N	0	0	27.3% (3)	63.6% (7)	9.1% (1)	3.78 (0.60)

All of the stakeholders were able to identify ways in which the quality of life of people with ADRD had improved. However, a few stakeholders commented that they had no objective way of measuring the impact of the Strategy on quality of life - there may have been improvements, but it was difficult to determine if these were directly because of the Strategy. Likewise, the full impact on quality of life is not known as some of the initiatives are still evolving. The staff education initiative and the role of the PRCs and PECs were identified as important to improving quality of life of people with ADRD and their caregivers.

The following provides a summary of the responses, by the specific initiatives that were identified.

Initiative	Impact on Quality of Life of People with Dementia and their Caregivers
#1: Staff Education (Overall)	▪ the Strategy has been successful in sensitizing and educating the workforce ▪ education of caregivers has enhanced their performance; staff are more knowledgeable and sensitive to their care provision ▪ through education both professionals and families help caregivers give better care ▪ education and support for in-house psychogeriatric resource people has promoted a higher standard of care, development of good tools and a common language
#3: PECs	▪ having one PEC within each Alzheimer Society Chapter has increased the amount of time and effort that education and support can be provided to clients (examples provided of the substantial increases in the number of support groups offered by Alzheimer Chapters) ▪ the PECs have promoted education and awareness ▪ the PECs have allowed chapters to recruit and train more volunteers and provide more service
#5: Caregiver Respite	▪ initiatives such as increased respite have improved availability of important supports ▪ additional day program spaces have provided activation for the moderately impaired, enabled individuals to remain in community longer, and provided caregivers with a consistent respite time
#6: Research on Caregiver Needs	▪ there is an improved understanding of caregiver needs
#7: Advanced Directives	▪ support for people with ADRD to be pro-active in making decisions about their care
#8: PRCs	▪ PRCs have been instrumental in improving the quality of life of clients as well as their caregivers ▪ PRC collaboration in long-term care homes has promoted a higher standard of care
#9A: Dementia Networks	▪ various projects initiated by the Dementia Networks (e.g., directory of services) have focused on supporting and improving quality of life of those with ADRD

Initiative	Impact on Quality of Life of People with Dementia and their Caregivers
	▪ in larger urban settings there are usually a daunting number of services, associations and organizations related to ADRD that can be confusing for those with dementia and their caregivers; the Dementia Networks have assisted people with ADRD, their family caregivers, and service providers to navigate through the maze of services available ▪ the Dementia Networks have given various services/organizations a better sense of the continuum of services that are available and provided a vehicle for them to work collectively together toward a common goal of improving service availability and delivery ▪ the Dementia Networks have identified gaps, reduced duplication of services and have promoted available services
Overall	***Quality of life for people with ADRD has been supported and enhanced by:*** ▪ increased awareness about ADRD through the Strategy – increased public and service provider awareness and increased awareness at a policy level ▪ increased awareness of the services available to people with ADRD locally and regionally ▪ increased access to and use of available services by service providers and family members ▪ family caregivers are better able to care for their loved ones because they are more knowledgeable ▪ enhanced linkages across the health care system, at the local, regional, and provincial level, among provider groups, associations, advocacy groups ▪ service enhancements ▪ promoting acceptance of the disease and dispelling myths reduced stigma because people now know it is a disease that you can do something about and therefore it is important to become better educated about it ▪ addressing the continuum of care from diagnosis, to respite, to long-term care ▪ addressing gaps that impact quality of life such as physician education, caregiver education, public education and respite

1b) Overall, how would you rate the success of the Alzheimer Strategy in terms of improving the treatment, care and environmental conditions of people with Alzheimer disease and related dementias?

(N=11)

	Poor 1	Fair 2	Good 3	Very Good 4	Excellent 5	Mean (SD)
% N	 0	 0	54.5% (6)	18.2% (2)	18.2 (2)	3.59 (0.85)

Overall, most stakeholders identified improvements in treatment and care, but indicated that changes to environmental conditions have lagged behind. Improvements to treatment and care were most often attributed to the staff education initiative and the PRC role. Issues related to the distribution of PRCs and PECs were identified.

The following provides a summary of the responses, by the specific initiatives that were identified.

Initiative	**Impact on Treatment, Care and Environmental Conditions of People with Alzheimer Disease and Related Dementias**
#1: Staff Education ▪ P.I.E.C.E.S.	▪ educational initiatives such as P.I.E.C.E.S. have been most important in improving treatment ▪ P.I.E.C.E.S. has resulted in providers speaking the same language, which did not happen prior to the Strategy, so that people can network better and provide better care, particularly CCACs and long-term care homes ▪ some frustration was experienced when front-line workers learned new care approaches, but could not adopt them because of lack of administrative support ▪ need more evaluation to determine if changes in care are sustained in the long-term
▪ Dementia Studies	▪ more successful in some areas than others; format not amenable to distance education; too basic a level for some learners
#3: PECs	▪ distribution of PECs by Alzheimer Chapter instead of the population base has resulted in some areas of the province having an inadequate number of PECs for the demand
#4: Appropriate Environments	▪ implementation of plans/designs for improving environmental conditions has lagged behind; not as far ahead as it should have been ▪ there has been some public education and education for staff on looking at the physical and social conditions but this was limited ▪ conference on design not a sustainable way of improving care and environment
#5: - Respite Services for Caregivers	▪ Adult Day Programs are not the only form of respite needed – some families require in-home respite
#8: PRCs	▪ PRCs have been important to improving treatment and care ▪ PRCs have been instrumental to linking clients to services, supporting and educating staff, but where not used as the role was intended, they have not been able to foster and support change champions within the system, such as the in-house psychogeriatric resource persons in LTC homes ▪ distribution of PRCs across the province needs to be reconsidered, particularly in

Initiative	**Impact on Treatment, Care and Environmental Conditions of People with Alzheimer Disease and Related Dementias**
	the North where the large geographic area poses a challenge to doing their jobs effectively ▪ there has been some inconsistency across PRCs in terms of the skills needed to fulfil their role; as a result, some PRCs have been better equipped to move the Strategy forward
#9A: Dementia Networks	▪ Dementia Networks have been important to improving treatment and care by bringing service providers together to improve and enhance care ▪ specific activities/projects developed by individual networks have become essential orientation tools or mechanisms for the public and professionals to become informed about dementia
Overall	▪ improvements in treatment, care, and environmental conditions has been variable across the province, and across systems of care; in some areas it is thought to be better than others ▪ treatment, care, and environmental conditions have been improved more so in institutional settings than in the community ▪ there have been improvements, but it's difficult to attribute these directly to the Strategy ▪ because some initiatives were implemented simultaneously, it was not possible to build upon what was learned (e.g., caregiver needs research and respite services)

1c) Overall, how would you rate the success of the Alzheimer Strategy in terms of increasing public awareness of dementia and the services available?

(N = 11)

	Poor 1	Fair 2	Good 3	Very Good 4	Excellent 5	Mean (SD)
% N	0	0	0	45.5% (5)	36.4% (4)	4.41 (0.58)

* Note: Two stakeholders abstained from providing a numerical ratings, preferring to provide a "don't know" response.

Education initiatives, particularly the PEC role, were identified as instrumental to increased public awareness. However, some stakeholders were not certain that overall increased public awareness of Alzheimer Disease could be attributed directly, or solely, to the Alzheimer Strategy.

Area	**Increasing Public Awareness of Dementia and the Services Available**
PEC impact on Public Awareness	▪ PECs have been an important part of the increased awareness of dementia ▪ designated funding to the PECs has allowed them to focus on promotion of ADRD so that awareness has grown tremendously ▪ many people were not aware of the existence of the Alzheimer Society prior to the development of the PEC position
Impact from other parts of the Strategy	▪ the public has become generally better informed due to the Strategy, and specifically because of the education of service providers in LTC homes through P.I.E.C.E.S., the PRCs, and physician education

Overall	▪ some stakeholders indicated that the Strategy has better informed providers and policy makers more so than the general public, who have become informed by the media and attention to celebrities who develop Alzheimer Disease (e.g., former United States president Ronald Reagan) ▪ Dementia Networks are an integral part of the awareness initiative ▪ physicians require greater awareness of the need for early diagnoses and services available ▪ need to provide awareness information to people before they need it – through senior groups, school curricula, etc ▪ need to continue efforts to reduce stigma ▪ need more awareness and training regarding the care of Aboriginal clients

1di) What benefits do you think will be realized over the next 3 to 5 years as a result of the Strategy in terms of supporting and improving the quality of life of people with dementia and their caregivers?

Although most stakeholders were able to identify benefits that will be realized in the short-term, many indicated that benefits would not be sustained in the long-term without continued support. Stakeholders discussed the process by which benefits of the Strategy related to supporting and improving quality of life for people with ADRD will be realized in the next few years.

The following provides a summary of the responses to this question.

Stakeholders reported that in the next 3 to 5 years there will be:

- an increased understanding of client needs (biomedical, psychosocial and environmental needs) and how to meet them
- improved knowledge and skills to support clients
- earlier diagnosis and access to services
- better educated service providers and caregivers because of the ongoing roles of the PECs and PRCs
- increased physician education as this initiative continues to be implemented
- an increased understanding that the quality of life of those with ADRD can be improved
- better informed family members (about services and the disease process)
- improved access to services because of improved linking of services across the system; the service system will be in a better position to respond to client needs
- improved access to the most appropriate services at the most appropriate time
- continued demand for education of staff, both institutional and community-based
- a more streamlined continuum of care

How these benefits will be realized:

- continued public education and education of service providers, both in institutional and community settings
- collaboration among providers within the Dementia Networks has resulted in the use of collective wisdom of individuals who are champions and innovators to move the field forward and has encouraged health professionals and organizations to work collaboratively
- the linking of service providers, policy makers, universities, educators, researchers, and advocates fosters a consistent and common vision, language, and approach for supporting those with ADRD

- regional collaboration and focus on the process of change
- through the work of the Dementia Networks
- by implementing the recommendations from the Research on Caregiver Needs Report
- advanced care planning training, which will assist people to plan for their care

Sustainability:

- continued support for staff education activities (e.g., P.I.E.C.E.S.) as well as PECs and PRCs, will be necessary for sustained benefits
- improvements made will disappear in 1 to 2 years without maturation of the Strategy, the continuation of knowledge, education, and putting benchmarks or sustainable mechanisms in place
- continued support for Dementia Networks is necessary to ensure that improved care and access to services are achieved; goodwill alone is not enough

ii) What benefits do you think will be realized over the next 3 to 5 years as a result of the Strategy in terms of improving the treatment, care and environmental conditions of people with Alzheimer disease and related dementias?

Although many stakeholders indicated that there have been profound changes in treatment and care for which benefits will continue to be realized, many did not think that there was sufficient attention paid to environmental conditions to realize or maintain change. Processes by which benefits of the Strategy related to treatment, care and environmental conditions of people with ADRD will be realized in the next few years were identified. Some stakeholders provided various suggestions for activities and resources necessary for long-term sustainability of benefits related to treatment, care and environmental conditions. Several indicated that the work of the Strategy in the past five years is only the beginning and more work needs to be done to build on and sustain achievements.

The following provides a summary of the responses to this question.

Stakeholders reported that in the next 3 to 5 years there will be:

- continued collaboration and partnering of services
- continued support provided by the PECs and PRCs
- awareness of the need for appropriate environmental conditions resulting from research conducted by the Murray Alzheimer Research and Education Project (MAREP), but a few stakeholders indicated that awareness alone will not result in change
- better understanding of what people affected with ADRD need at the time of early onset
- improved treatment and care due to increased knowledge and skills of long-term care staff, community agency staff, physicians, and informal caregivers as a result of dementia specific training and development

- service providers and family members will be better trained so that they will not be as overwhelmed with some of the circumstances they face
- more involvement of physicians and specialists in case management and development of holistic treatment approaches
- more specialization of staff functions to ensure appropriate treatment and care; increased involvement of family members in these approaches
- stronger linkages amongst service providers created through Dementia Networks will assist in improving the delivery of services

- better treatments to arrest the progress of the illness
- different ways to support people at home; different ways to support people when they are institutionalized; better types of care
- improved drug therapy
- greater sensitivity to the needs of those affected with ADRD due to greater public awareness
- reduced stigma and social isolation so that more people will access needed services
- gaps in service delivery will be identified and addressed

How these benefits will be realized:

- initiatives of the Dementia Networks that will enhance continuity of client care and that will strengthen the treatment process
- use of the best literature to make change
- ensuring that there are change champions in various sectors that work together to exchange knowledge and to support people with dementia by bringing them the best knowledge at the best time
- emphasis on research and transfer of new knowledge into clinical practice
- ongoing development of assessment tools
- continued efforts of the PECs and PRCs who are the foundation of change in how ADRD is treated
- breakdown in communication barriers between partners and physicians

Long-term sustainability related to treatment, care and environmental conditions will require:

- development of a process for sharing ideas and resources and linking organizations with similar interests (e.g., website or human resource supportive process)
- incorporation of 'lessons learned' into educational programs regarding the design of environments and access to these lessons by policy makers who are developing regulations for LTC homes
- long-term commitment to physician education
- continued support to Dementia Networks to initiate projects with the aim of improving coordination of care
- more funding for research directed at improving treatment, and specifically at developing treatments that have a longer lasting effect
- more support for improvements in dementia care within acute care settings because currently there are inconsistencies in quality of care across different systems of care

iii) What benefits do you think will be realized over the next 3 to 5 years as a result of the Strategy in terms of increasing public awareness of dementia and the services available?

Several stakeholders commented that increased public awareness was the foundation for many of the changes realized as a result of the Strategy. Some stakeholders indicated that benefits related to public awareness would be realized primarily because of educational initiatives and the Alzheimer Society of Ontario's public awareness campaign. Although many stakeholders indicated that there has been a significant increase in public awareness, they acknowledged that more work was still needed to promote public awareness and accessibility to services. There continues to be limited access to services because of lack of awareness and understanding of dementia, stigma, social isolation, and withdrawal from services when providers lack knowledge and comfort with ADRD.

The following provides a summary of the responses to this question.

Stakeholders reported that in the next 3 to 5 years there will be:

- changes to the political climate in regards to health care services and repositioning of our health care system to deal with the increasing needs for care of the elderly
- increased support of the efforts of the Alzheimer Society by various service organizations and agencies
- increased cooperation between public services and those in the community with ADRD (e.g., taxi drivers, police)
- increased coordination between various groups in terms of public awareness activities
- increased access to information in very remote areas of the province
- increased awareness of available services (e.g., day programs, information services, respite), resources, and treatments (both by clients and service providers)
- increased access to services
- increased understanding of dementia as an entity and not just due to age
- improved attitude toward and increased acceptance of those with ADRD
- increased comfort level of health professionals dealing with ADRD
- less stigma and fear about ADRD increasing the likelihood that people will seek diagnosis and treatment sooner
- increased emphasis on pharmacological and non-pharmacological treatments
- increased emphasis on the needs of family caregivers so that services for family caregivers are expanded
- increased awareness within long-term care homes of the services available to them
- individuals and families accessing service earlier in the disease process
- individuals and families knowing where to turn for support
- improved linkages among service providers
- more involvement of the general public in developing responses and providing support

How these benefits will be realized:

- through the work of PECs (public lectures, staff training) and PRCs (assistance to LTC homes and community agencies to better manage ADRD)
- collaboration between PECs, PRCs and the Dementia Networks – a specified alliance among these groups

2) What have been the major strengths of the Alzheimer Strategy?

Many stakeholders commented that the Strategy has accomplished a tremendous amount in five years. The Strategy was described as creative and innovative, primarily because of its multifaceted and multi-sector approach. Most commonly, education initiatives were identified as major strengths. The major strengths of the Strategy, as identified by the stakeholder groups, can be categorized into three main theme areas: planning process, development and implementation, and Strategy outcomes. A summary of the responses in each of these themes follows.

The planning process:

- multifaceted approach
- designed across sectors
- it was a comprehensive plan supported by top levels of government
- dedication of resources, both human and financial to implement the Strategy initiatives
- collaboration and partnerships between services, agencies, and systems of care
- multi-level linkages: from provincial to regional to the local level
- the marriage between service, education, research, and policy
- a systematic approach to dealing with the many issues related to dementia and care for those affected
- 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
- there is strength in the process that was used and the timely evaluation of progress
- the inter-ministerial approach has helped to ensure that there is a sense of common purpose and direction and a pooling of resources
- reduced competition/territoriality between service providers to create open dialogue

Development and Implementation:

- commitment to physician education
- consultation process with key stakeholders
- the empowerment of agencies and service providers to do more and do better than prior to the Strategy
- development and implementation of specific strategies:
    - PRCs
    - P.I.E.C.E.S. and U-First initiatives and related resource material to support staff in LTC homes and community agencies
    - PECs
    - Dementia Networks
- the willingness and openness of the individuals that have been involved in the Strategy
- support to champions
- research into community needs assessment
- the initiatives were adaptable at the local level, recognizing the needs of various communities and created opportunities for regional projects
- the Strategy brought together all stakeholders in a team effort, rather than in a competitive environment resulting in open dialogue
- follow through with the plan
- included networking with partners that would not have been obvious partners
- shared vision and commitment contributed to perseverance despite challenges

Strategy outcomes:
- putting ADRD on a major agenda for the government
- increased public awareness of services available
- increased public awareness of the activities of the Alzheimer Chapters and particularly, the partnerships between the Alzheimer Chapters, CCACs, community agencies and LTC homes
- stronger relationships among service providers
- development and use of a common language and a common approach in response to ADRD across the province
- breakdown of the separation between regulated and unregulated staff in LTC homes – the coming together to achieve a common mission
- enhanced knowledge and skills of health providers
- improved advocacy
- the opportunity to use the best knowledge in terms of theory and experience, in education and clinical practice
- collaboration among different sectors of the health care system; willingness to put aside territoriality issues to examine needs across the system
- commitment from many people to maintaining the momentum and continuing to move the Strategy forward
- increased education of service providers and caregivers
- increased dialogue between decision makers and knowledgeable organizations such as the Alzheimer Society
- public awareness about the disease removed barriers to care both in the community and within the health care system
- reduced stigma
- elder care in Ontario will get a higher priority

3. What limitations have there been (or what areas require improvement)?

The limitations of the Strategy, or areas requiring improvement, as identified by stakeholders pertained primarily to the implementation of the overall Strategy, involvement of certain sectors, sustainability, health system issues, access to services, research initiatives, and implementation of specific initiatives. A summary of stakeholder responses follows.

Implementation
- limited funding in the long-term care system to implement specific initiatives (e.g., environmental redesign, implementation of new care approaches)
- underestimation of time required for planning prior to the roll-out of initiatives
- 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)
- consultations should have occurred with all stakeholder groups prior to allocation of resources

Limited involvement of certain sectors
- lack of participation of sectors that were not receiving funding from the MOHLTC (e.g., retirement homes)
- limited participation of acute care system in education, particularly emergency room workers
- acute care settings require the support of a position like that of the PRC to improve the quality of care that people with ADRD receive in these settings.

Sustainability

- the achievements of the Strategy have not always been integrated into daily practice; there are no set standards regarding the implementation of new knowledge into practice, or have been limited shifts in organization support to ensure sustainability
- while particular changes that need to occur to sustain the benefits of the Strategy have been identified, there is a sense that these changes can occur without: extra funding, changes to funding formulas (which most likely will not occur), and/or changes in attitudes within organizations related to accountability
- lack of an overarching framework or vision for ongoing activities to support ADRD
- not clear how initiatives will be sustained

Health system issues

- planning of various parts of the system is fractured (e.g., a change in the mental health system is not considered in terms of how it will affect or compliment a change in the community)
- gaps in the provision of geriatric services in the province
- over-regulation in long-term care homes limits flexibility around some initiatives (e.g., environmental design)

Access to services

- the stigma associated with accessing services still exists
- in some parts of the province, particularly rural and remote areas, there continues to be a lack of day programs, respite, caregiver support, and transportation (limiting access to programs and services)

Research initiatives

- the Research Coalition has not moved forward as quickly as it should have to build a stronger and competitive position for research in Ontario
- there is a need for more research into the environment and supports needed to optimize care of seniors with cognitive and physical impairment
- limited research to verify to what extent the guidelines for an appropriate safe and secure environment translate into improved quality of life from the client's perception
- limited outcomes evaluation; limited impact measurements
- limited funding for research on care approaches to manage individuals in their homes; most of the current research is institution-based

Initiative #1: Staff education

- limited access to training by front-line LTC staff in rural and remote areas
- limited number of P.I.E.C.E.S. trained staff in long-term care homes per number of residents
- under-utilization of P.I.E.C.E.S. staff in long-term care primarily due to lack of designated time for P.I.E.C.E.S. related activities (assessment, data collection, consultation with PRC) and lack of organizational support for change

- lack of organizational support for the implementation of the P.I.E.C.E.S. program within LTC homes has resulted in the P.I.E.C.E.S. program not being utilized to its full potential in some areas

Initiative #2: Physician training

- physician participation and buy-in has been a challenge for particular communities, primarily because remuneration limits their willingness to participate and because of the physician shortage (physicians are too overworked and stressed to take on anything new)
- limited movement on the physician education initiative
- limited continuing education for physicians
- limited continuing education for physicians in certain geographic areas

Initiative #3: Public awareness, information, and education
- PECs require resources for administrative activities
- increased awareness has led to increased demand for service, but no increase in the number of positions to meet need
- intense workload of PECs increases their risk for burnout
- disproportional distribution of PEC across geographic regions/population density

Initiative #4: Planning for appropriate, safe, secure environments
- conference not a sustainable way of improving care

Initiative #5: Respite Services for Caregivers
- there was not a strong focus on supports for families; strategies that emphasize the need for full family support that includes children is important
- research on caregiver quality of life indicates the need for greater emphasis on community support for caregiver relief and in-home care supports

Initiative #7: Advance directives on care choices
- advanced care planning initiative has not taken off as well as it should have; challenges exist related to how to “package’ it for the public and how to fit it into other initiatives

Initiative #8: Psychogeriatric Consulting Resources
- some areas in the province could have used additional PRC positions
- some role confusion between the PECs and PRCs

Initiative #9a: Dementia Networks
- there is variability across the province in how effective the Dementia Networks are awareness of services, coordination of services, access to services, clarity around who does what, still need to be addressed; there is a need to tie all service providers and professionals in the field into a common planning and delivery coordination process

Initiative #9c: Specialized geriatric services
- limited attention paid to Initiative 9c related to the review of Specialized Geriatric Services
- Ministry of Health and Long-Term care has not yet responded to recommendations from the expert panel on the review of Specialized Geriatric Services

4a) How would you rate the Alzheimer Strategy in terms of its success in improving linkages and collaboration within the system of care (i.e., between service providers, educators, researchers, policy makers, agencies, organizations, advocacy groups, and/or networks)?

(N=11)

	Poor 1	Fair 2	Good 3	Very Good 4	Excellent 5	Mean (SD)
% N	 0	9.1% (1)	9.1% (1)	63.6% (7)	18.2% (2)	3.84 (0.84)

There was general agreement the Alzheimer Strategy has resulted in improved linkages and collaboration within the system of care – linkages that may not have occurred otherwise. Some stakeholders expressed concern about the sustainability of these linkages in the long-term and some indicated that there is still much more work that needs to be done to achieve Strategy objectives. In response to this question stakeholders discussed the impacts of established collaborations and linkage, limitations, and issues related to sustainability. Their responses are summarized below.

Impacts of collaboration and linkages

- 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 (e.g. the Dementia Networks were identified as an example of this)
- increased dialogue and communication across the continuum of care; increased collaboration across the system
- 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 and fear of losing funding when its apparent that others provide the same service
- 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
- service providers feeling better supported
- organizations/agencies that otherwise would not have been invited to participate in consultations now have a seat at the table so they have been able to establish their credibility in the field
- increased collaboration between service providers and caregivers in terms of planning and coordination

Limitations / Areas for Improvement

- limited linkages between researchers and services providers
- ensuring that research is applicable to care that is provided is a challenge –there needs to be a better link between clinicians and researchers, ensuring that the questions that clinicians ask are addressed by research
- Dementia Networks still need to address the in-depth needs for coordination of services and improved planning
- there were no existing mechanisms to make forging linkages in larger urban settings easier – establishing these linkages was challenging due to territorial issues
- the policy makers are not evident to caregivers; the Strategy was an initiative, but there is no clear policy that is going to link this initiative with an elder friendly strategy for the province
- limited involvement of acute care and physicians

Sustainability

- more work still needs to be done by the Dementia Networks
- linkages, referrals and information sharing are improving, however there is a need to involve more key decision makers within the various sectors that provide services, both at a provincial and regional level in order to have more collaboration take place around long-term planning and coordination, and to make significant change at a system level
- need to continue to forge linkages with local universities to collaborate on research, including evaluation research

b) What benefits do you think will be realized over the next 3 to 5 years as a result of these linkages /collaboration, if any?

Overall, most stakeholders reported benefits related to service delivery, namely more efficient health care service delivery. Some stakeholders identified ways in which these benefits would be realized, indicating that linkages and collaborations would require some attention in order to sustain benefits.

Benefits to be realized over the next 3 to 5 years:

Improved service delivery

- reduced duplication of services, which results in more efficient use of resources
- strengthening of continuity of care, particularly with e-health, so that people will be less isolated and more supported; a seamless health care system
- easier and quicker access to services
- availability of services for a longer period of time
- better planning and coordination of services
- reduced silos between organizations, which will result in a better coordination of services, greater information about and access to services
- better and more efficient service delivery
- service providers will be better able to identify the onset of ADRD and more confident in their ability to care for those with ADRD

Continued collaborative efforts

- increased partnering and sharing among services
- stronger local networks and linkages than in the past
- better communication and collaboration between service providers to help fill gaps and initiate new services
- examples were provided of how people in different sectors and organizations share resources

Improved awareness and training

- staff and families will be better educated and informed about available services
- increased education to staff in all sectors
- more joint conferences and seminars to increase understanding of dementia

Improved data collection

- development of user-friendly documents for families and service providers
- development of a common assessment tool, the results of which will be shared across organizations to avoid duplication of assessment
- research based on concerns and needs of family caregivers

How these benefits will be realized:

- integration of the Strategy into the overall health system; development of an overall vision and framework for the elderly
- continued "fuelling" of the system – continued provision of information to people that will use it
- continued support, or incentive because the benefits will not be sustained by goodwill alone
- there is a need to explore the possible benefits of using an approach that emulate or builds on the experience of District Health Councils and high level planning task forces

5. How would you rate the Alzheimer Strategy in terms of the impact it has had on the members/constituents in your association/organization?

(N=11)

	Poor 1	Fair 2	Good 3	Very Good 4	Excellent 5	Mean (SD)
% N	 0	 0	27.3% (3)	54.5% (6)	18.2% (2)	3.91 (0.70)

Staff education activities (e.g., P.I.E.C.E.S., U-First) and the roles of the PECs and PRCs were identified by many stakeholders as having had a significant impact on the members of their organizations. Dementia Networks were also identified as contributing significantly to the development of linkages among organizations and with communities. Although a few stakeholders indicated that while the Strategy may not have had a great impact on the members of their specific organization, they recognize that the Strategy had a positive impact in the communities they serve. A summary of stakeholders' comments follows.

Impacts of the Strategy on association/organization members:

Increased education, training and increased awareness

- increased awareness of dementia
- increased information about ADRD
- improved care and the development of best practices
- increased accountability
- identification of ongoing needs, planning, and services to meet these needs
- at a national level, other provinces are beginning to adopt some of the educational components and linkages that have been successful for the Strategy in Ontario
- improved physician practice; increased confidence in dealing with ADRD
- increased education provided to families resulting in better access to information about all aspects of dementia; agencies and individuals have increased access to information
- improved care through staff education and the PRC program, increased knowledge through new educational opportunities for service providers, having an avenue to help effect change through participation in the Dementia Network, less stigma through increased public awareness
- improvements in family caregiver services through knowledge gained in the research on caregiver needs

Linkages and collaborations

- increased awareness of what each service can and cannot do; increased awareness of existing gaps in services

- recognition of the need to develop common goals in order to identify the potential collaborative activities to achieve those goals
- Dementia Networks have impacted members through the linkages created
- the Strategy created a great deal of excitement and cohesiveness among stakeholder association / organization members

Miscellaneous
- governing bodies have taken more of an interest in dementia than they did a few years ago
- additional day programs were an identified need that was welcomed
- increased respite care being available for clients
- increased outreach and awareness has led to increased fundraising ability of the Alzheimer Society Chapters

Limitations
- it has taken some time for the PRCs to form linkages with some organizations, but this has been established and will hopefully continue

6. What supports do you feel are required over the next 1 – 2 years to allow the Strategy initiatives to attain their maximum potential?

Respondents identified a number of key supports to help ensure the Strategy initiatives attain their potential. The primary supports identified include: access to the most recent information regarding best practices and ensuring that this information is shared with physicians, service providers and caregivers; knowledge transfer – ensuring that what's learned from research is shared with providers; facilitation of ongoing learning; support for more research into the care system, best practices, etc.; continued support of change champions; and ensuring that structures exist to facilitate communication among provincial, regional and local groups.

The following is a summary of the needed supports identified by the stakeholders.

Information/education
- access to library services, particularly for PRCs and Dementia Network members, to obtain information necessary to support the development of best practice guidelines and to conduct thorough literature searches on relevant topics
- continued access to up-to-date information and education
- resources to ensure that caregivers and family caregivers get more education
- continued commitment to physician education
- continued training, particularly to key sectors such as acute care
- development and implementation of the knowledge exchange to support change champion positions such as the PRCs and PECs; a knowledge exchange that connects people, not that simply disseminates information (i.e., not just a website)
- need to focus on knowledge transfer, ensuring change in clinical practice is evidence-based
- ongoing central development of educational tools to reduce preparation time and costs to educators
- increased opportunities for students (high level, nursing and medical students) to work with the elderly and incentives to study diseases of the elderly

Research and evaluation
- establishment of a viable Research Coalition and a viable research agenda for Ontario related to ADRD to provide the data necessary to support and sustain elements of the initiatives
- increased outcomes research, including how people get care, where they are successful and

unsuccessful

- there is a need for more analysis of what the system of care looks like, what it provides and does not provide, and how it works or does not work in concert, in order to help address the health of the system of care and how it should develop in the future to meet the needs of those with dementia

Support for specific initiatives and activities

- continued funding for dedicated time for leaders and champions to move initiatives forward, because without them activities will terminate
- continued support for individuals that are involved in linking people at the provincial, regional, and local levels
- respite support for family caregivers; more options for respite including in-home respite
- there is a need for continued support for the work that has been initiated under various strategies, including P.I.E.C.E.S., U-First and the physician training initiative

Policy/system changes

- ongoing provincial policy process with emphasis on more integration among various sectors
- primary care reform from a population health perspective; need to improve chronic disease management
- there needs to be a coordinated approach for care of the elderly in general, not just disease-specific approaches
- need to better connect acute and long-term care service sectors
- more focus on engaging key decision makers in the planning process for an effective system of care
- continued policy liaison with the government

Communication structures

- the implementation of a communication structure to support the timely exchange of information between Dementia Networks, the Roundtable and the Provincial Alzheimer Group would enhance ongoing planning and evaluation processes
- there is a need for a communication structure to be put in place that establishes stronger communication linkages for information sharing between Dementia Networks across Ontario in order that each can learn and benefit from other networks' successes and lessons learned
- improved communication between researchers, clinicians, and service providers to enhance knowledge transfer to clinical practice

Miscellaneous

- opportunities to learn from lessons
- continued provincial coordination through the Dementia Networks, regional bodies, and government partners
- more support for collaborative efforts in rural and remote areas where the logistics of meeting, networking, and working together is challenging
- investment in services for the elderly in general
- development of a Centre for Excellence in Dementia Care

7. Did you attend the Invitational Alzheimer Strategy Workshop: Coming Together to Shape the Future in April, 2004?

Yes: 70% (N = 7) → Do you feel that the results of this consultation will sustain the successes resulting from the Strategy?

Yes: N = 4
No: N = 2
Unsure: N = 1

Generally, stakeholders commented that the successes of Strategy will be sustained if major activities that were identified in the consultation as necessary to move the Strategy forward are supported and implemented. In addition, stakeholders identified the key supports necessary to sustain the successes resulting from the Strategy. The following is a summary of the comments made by the stakeholders.

Key supports

- development of a Provincial Alzheimer Group that would be responsible for governance, linking of people at the provincial level, and supporting sustainability and integration
- development of the Alzheimer Knowledge Exchange to facilitate awareness, support web driven activities, and dissemination of knowledge into the field
- development of a broader vision of care that includes an examination of the broad determinants of health
- continued educational activities
- accountability for the positions that have been developed as a result of the Strategy

Concerns about the workshop:

- the emphasis was on sustainability, without examining the fundamental changes that need to occur within the system in order for sustainability to occur (e.g., funding, incentives, system changes within CCACs, LTC homes, acute care)
- emphasis was on building on what the Strategy has done so far, but less attention was paid to what hasn't been done – what needs remain and how to respond to these needs
- the workshop generated a lot of ideas, but should have included consensus on a specific set of key priority recommendations

Those who did not attend the Alzheimer Strategy Workshop (N = 4) were asked: What are the two most important actions to sustain the successes resulting from the Strategy?

The following is a summary of the comments made by these stakeholders.

- continued planning, and strategizing for the future (Provincial Advisory Group, Roundtable)
- establishment of a functioning Research Coalition
- ongoing physician education
- a broader policy for the care of the elderly and development of senior friendly environments
- continued funding by the Ministry of Health and Long-Term Care, particularly for successful programs
- continued advocacy for appropriate services for people with ADRD through public policy
- continued recognition of the need for research and fostering good research opportunities
- ongoing funding that's embedded in the annualized funding from the Ministry to support initiatives in the geriatric area, particularly on geriatric education
- continued work by the Dementia Networks
- continued P.I.E.C.E.S. training and support to long-term care home staff and the PRC position
- staying true to the Strategy and building on its success
- seeking to involve as wide a range of stakeholders as possible with a focus on those in decision-making roles within the community
- maintaining more than acceptable standards of service

8. One of the initiatives arising from the Strategy is the creation of a Roundtable that will develop a planning framework to address the needs of people affected by Alzheimer Disease and Related Dementias (ADRD) in the context of the determinants of health and healthy aging. What are the three most significant areas that should be included in the planning framework if it is to improve the overall quality of life for people affected by ADRD?

There was some concern that there is a lack of clarity around the objectives of the Roundtable, however, there was an overriding belief that there is a need for the Roundtable and in particular the development of a framework guided by clear principles and objectives, and that occurs within the context of a broad plan for the care of the elderly. The following is a summary of the comments made by the stakeholders.

Significant areas to include in planning:

Framework development

- a clear vision that identifies the principles that will move the initiative forward, including people with ADRD and their caregivers in a dialogue about their care and planning of their services
- development of a framework, guided by clear principles and policy, that is applied at the local community level so that there is a healthy response to people with Alzheimer Disease, especially stressing the importance of early detection
- development of a framework that would be comprehensive and integrated with the rest of the health care system
- future planning should be informed by ongoing research that examines what has been achieved with the initiatives; a well supported coalition of researchers with a clear agenda that is relevant to Ontario, can develop the infrastructure, the direction, and gather the data to be able to support and inform the planning process
- the Roundtable planning process needs to occur in the context of a broader strategy for seniors that addresses the determinants of healthy aging, primary and secondary prevention, and senior friendly environments
- involvement of those with ADRD in the planning process
- continued identification and involvement of key stakeholders
- initiatives linked with a broader elder care framework
- having people at the table who can take action, allocate resources, affect change within the global community

Education/awareness

- physician education – quality of life of patients is diminished when their physicians are not aware of what services are accessible in their community
- greater emphasis on maintaining independence in the home setting
- strong government support for public awareness
- public awareness and education for those providing care including physicians, nurses, PT, OT, social workers and other service providers using a common language
- continued dissemination of knowledge and information in an effective way to patients, families, caregivers, and professionals to reduce the gap between research and application of new information
- public awareness leading to “dementia friendly” communities

Service delivery

- an examination of access to services; how access can be facilitated
- equal access to services in all communities across the province

- emphasis on client-centered service
- understanding of the demographic impact on service delivery
- providing a better continuum of care within the long-term care system to make it easier for people with ADRD to travel through the system
- more emphasis on integrated health services, with a focus on home care and community
- the establishment of a regional health authority that would have the authority to increase the efficiency of the health system; to make efficient use of current funding; to create formal linkages (accountability) among various organizations and services to ensure cooperation, collaboration, and coordination of services (This was identified as particularly relevant in larger urban settings where there are many different types of organizations providing dementia services.)
- cross-sector integration
- need to address the issue of physician shortage, particularly the shortage of geriatric specialists, especially in Northern areas because this will soon be a crisis situation
- a long-term plan for dealing with the stigma that continues to exist: how to deal with stigma and it's effects so that there will be access to transportation, education, health care, and support of local communities
- emphasis on health rather than illness; focus on what people can still do not what they are losing
- more emphasis on supportive end-of-life care in long-term care homes
- attention to access to specialized geriatric services
- recognition of the importance of early diagnosis and treatment of depression
- proactive approach/adjustment to life changes occurring with age
- increase number of Personal Support Workers, Registered Nurses, Registered Practical Nurses (reduce shortages)
- equitable remuneration for service providers in community and long-term care sector

Caregiver support
- support for caregivers and service providers through education, dialogue and communication, awareness of available resources
- continued support for family caregivers; respite plans tailored to the needs of caregivers; measures to cope with stress
- system linkages that provide continuity of care responding to diversity of needs

Research and evaluation
- evaluation research and quality improvement initiatives
- maintaining a concentrated research initiative
- more long-term care specific research, particularly related to the management of behaviour
- research about quality of life from the client's perspective
- research on respite needs (evidence that respite reduces caregiver burden and reduces healthcare costs)
- research on ADRD, treatments, and needs of those with ADRD
- funding for bio-medical research

9. Do you have any other comments about the Alzheimer Strategy or its impact?

Many stakeholders commented that the Alzheimer Strategy has been the most intensive investment of time and resources of any health care initiative to date. Despite this, some stakeholders view the Strategy as a beginning with more work still left to be done to improve the care of those with ADRD. Some stakeholders emphasized the need to continue to enhance and build upon the successes of the Strategy.

The following is a summary of the comments made by the stakeholders.

The Strategy has been responsible for a number of events/activities that would not have occurred otherwise:
- an increase in the number of people served since the onset of the Strategy
- education (amount and level) within the community and in long-term care homes
- development of a common focus to look at improving the system of care, not only for dementia care, but geriatric services for the whole region
- the bringing together of people from across the spectrum of care, both regionally and locally, to dialogue and plan
- a greater appreciation of the impacts of the disease on families

General comments:
- the government will need to develop a deliberate focused plan to continue to build on the successes of the Strategy
- the Strategy is a model that could be used for other chronic diseases
- the Strategy was successful because it was broad; it was not a “one hit wonder”
- it was money well spent
- it was innovative of the government to take it on
- this is a very important initiative; the government is to be congratulated on its quality and thoroughness
- the Strategy took a quiet, personal, and shameful struggle and made it a collaborative community crusade toward dignity and understanding

Sustainability requirements
- broader changes in the health sector to drive changes – some of the initiatives (e.g., Dementia Networks) will be vehicles for change, but they won’t necessarily be the driver of those changes
- a broader strategy or policy direction for the care of the elderly that involves specialized geriatric services in the consultation and planning process
- integrated planning for care and development of regional health authorities similar to the models based in Alberta and New Brunswick
- need for continued evaluation – to determine what’s working and what’s not
- legal direction/support for adapting long-term care needs to accommodate personal legal rights (advance directives)

APPENDIX A

List of Participating Key Stakeholder Associations/Organizations

Alzheimer Society of Ontario

Canadian Coalition for Seniors' Mental Health

Dementia Networks:

- Cochrane County
- Durham County
- Hamilton County
- Huron County
- Renfrew County
- Toronto
- Wellington Dufferin County

Ontario Association for Non-Profit Homes and Services for Seniors

Ontario Association of Community Care Access Centres

Ontario College of Family Physicians

Ontario Community Support Association

Ontario Home Care Association

Ontario Long-Term Care Association

Regional Geriatric Programs of Ontario

Regional Geriatric Psychiatry Programs on Ontario

APPENDIX B

Summary of Post-Strategy Activities

Roundtable on Future Planning

The purpose of the Roundtable is 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

The Provincial Alzheimer Group (PAG) is 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.

Alzheimer Knowledge Exchange

A proposal for the **Alzheimer Knowledge Exchange (AKE)** has been 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.

Dementia Networks

Dementia Networks will serve as vehicles for maintaining effective two-way communication among the local organizations/providers and between the local system and the Roundtable and PAG.

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