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

REPORT #1:
SUMMARY OF STAKEHOLDER INTERVIEWS

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BACKGROUND

In order to gather information on what impact the Alzheimer Strategy has had thus far, including the identification of some of its successes and areas requiring improvement, a number of interviews were conducted with key stakeholder associations / organizations from across the province between February and April 2003.

The interview questions were developed by the Evaluator in conjunction with members of the Initiative Representatives Committee, a subcommittee of the Provincial Advisory Committee. The questions focused on: assessing the impact of the strategy to date (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 list of key stakeholder associations / organizations was compiled by the Initiative Representatives Committee. 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 Initiative Representatives Committee was interested in understanding the impact of the Alzheimer Strategy from the perspective of their members / constituents.

A total of 14 stakeholder groups were identified and each of these groups participated in the interviews.

For some questions, stakeholders were asked to rate certain aspects of the Strategy. A total of 13 of the 14 stakeholders provided ratings. As a result, a denominator of 13 was used to calculate percentages. As well, for some stakeholder groups, more than one person was interviewed, 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).

The following provides a summary of the feedback obtained. 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.

SECTION 1: HIGHLIGHTS EMERGING FROM THE STAKEHOLDER INTERVIEWS

- Overall, stakeholders reported that many benefits had been realized thus far as a result of the Alzheimer Strategy. When asked to rate the success of the Strategy on a scale of 1 to 5 (where 1 = ”poor”, 2 = “fair”, 3 = “good”, 4 = “very good” and 5 = “excellent”):

    - 92.3% rated the success of the Strategy as “good” or “very good” in terms of supporting and improving the quality of life of persons with dementia and their caregivers;

    - 92.3% rated the success of the Strategy as “good” or “very good” in terms of improving the treatment, care and environmental conditions of persons with Alzheimer disease and related dementias; and

    - 61.5% rated the success of the Strategy as “very good” or “excellent” and another 23% rated it as “good” in terms of increasing public awareness of dementia and the services available.

- Effective collaboration among service providers, educators, researchers, policy makers, agencies, organizations, advocacy groups, and/or networks was considered one of the biggest successes of the Strategy.

    - 76.9% rated the Alzheimer Strategy as “very good” or “excellent” in terms of its success in improving linkages and collaborations within the system of care

    - the participants noted that some very productive working relationships had developed, many among providers who had never worked together before

    - the participants noted that these collaborative relationships help to increase knowledge about what services and supports are available to persons with dementia and their caregivers, as well as increase knowledge about the mandate of these services; this, in turn, leads to more appropriate referrals and better use of resources

    - it was also noted that as a result of these collaborations, a synergy has developed – that the total is greater than the sum of its parts.

- The stakeholders also recognized that in many ways, the Strategy was still in the earlier phases of development and that greater benefits were likely to be realized as the various initiatives continued to roll out and evolve.

- There was a commonly raised concern about being able to sustain the successes that have been realized. The stakeholders indicated that, particularly with the changing demographics, specific mechanisms and supports need to be in place at the end of the Strategy if the benefits that have been realized are to continue and expand.

- The comprehensiveness of the Strategy (i.e., having initiatives that address service, education and research) was one of the key success factor of the Strategy. Alzheimer disease and other dementias (ADRD) are complex, multidimensional diseases that need to be addressed through multiple methods.

- The Strategy has led to an increase in the number of well-trained staff (resulting particularly from the P.I.E.C.E.S. training, Dementia Studies courses, and the PRCs). More knowledgeable staff leads to better care for persons with dementia, and begins to set higher standards for care.

    - however, it was recognized that more opportunities need to be available for unregulated health care providers (although the *U-First!* initiative may help to address this)

    - there was also a recognition of the need to enshrine the role of the In-House Psychogeriatric Resource Person (PRP) (e.g., set expectations, have funding for dedicated time).

- The Strategy has also lead to an increase in awareness among the public, family members, caregivers, service providers, and government. Increased awareness will:

    - help to reduce the stigma associated with ADRD and

    - help to increase understanding about the disease and the needs of those with the disease and their caregivers.

- The Strategy has increased the number of services and supports to persons with dementia and their families; although, there has likely been a greater impact on care and treatment than on environment.

- While there have been many benefits, there are also some areas requiring improvement:

    - there is some variation in the success of certain initiatives across the province (e.g., P.I.E.C.E.S.); more time is needed to see the potential benefits

    - there is a need for more respite options (e.g., in-home paid respite)

    - because Initiative #2 – Physician Training has taken longer to roll-out, there needs to be a continued focus on improving educational opportunities and ensuring buy-in from physicians

    - the hospital sector has been left out; hospital staff are in need of education regarding ADRD

    - there is a need to address multicultural issues

- the participants indicated that they hoped the evaluation would address the appropriateness of the decisions used to allocate the PECs and PRCs

- there has been no action on the recommendations arising from Initiative #9C – Specialized Geriatric Services

- there is a need for a comprehensive strategy for the frail/complex elderly

- there is a need for continued funding to enable components of some initiatives within the Strategy that are not part of base funding to continue (e.g., some components within the staff training and physician training initiatives); such funding is essential because of the demographic challenges that will be faced in the near future

SECTION 2: DETAILED SUMMARY OF RESPONSES FROM STAKEHOLDER INTERVIEWS

1. Overall, how would you rate the success of the Alzheimer Strategy *to date* in terms of the following:

a) Supporting and improving the quality of life of persons with dementia and their caregivers?

Poor 1	Fair 2	Good 3	Very Good 4	Excellent 5	Mean (SD)
0	7.7% (1)	30.8% (4)	61.5% (8)	0	3.50 (0.58)

* Percentages may not sum to 100% because of missing values.
** Note: Frequency values have been rounded.

Summary of Comments:

A few respondents indicated that they were unable to provide feedback on this question either because they had minimal contact with persons with dementia and their caregivers (but rather, had more contact with service providers), or because they thought it was too early to know what impact, if any, the Strategy has had in this area.

Most individuals, however, provided a response to this question. The responses were generally framed as "if X is improved, quality of life is/will be enhanced". This is likely due to the difficulty in assessing and measuring quality of life.

The following provides a summary of the responses, by initiative.

Initiative	Impact on Quality of Life of Persons with Dementia and their Caregivers
#1: Staff Education	
▪ P.I.E.C.E.S.	▪ there has been an impact in the quality of life of LTC residents because of the role the P.I.E.C.E.S. trained individuals (i.e., In-house PRPs) have with residents ▪ an example was shared of how the In-house PRPs help new residents adjust to their new environment ▪ example shared that In-house PRPs provide a link to external resources
▪ Support for Enhancing Care & Dementia Studies	▪ support has helped to entice partners to commit to enhancing knowledge and skills of staff ▪ support has helped to increase competence of staff which impacts on quality of life
▪ U-First!	▪ too early to know
▪ Overall	▪ this initiative has helped to increase knowledge of dementia among service providers which has an impact on quality of life
#2: Physician Training	▪ too early to know impact ▪ has helped to revitalize the focus of dementia within the faculties of Health Science (which indirectly impacts on quality of life)

Initiative	Impact on Quality of Life of Persons with Dementia and their Caregivers
#3: PECs	▪ impact on quality of life as a result of education and support provided to persons with dementia and their caregivers; education and support assists them in making better decisions and helps caregivers to cope with stress; stress of caregiver directly effects the person with dementia ▪ role has also helped to increase knowledge of staff from LTC facilities and community agencies
#4: Appropriate Environments	▪ some impact on LTC facilities and other environments that serve older persons
#5: Caregiver Respite	▪ more services have been provided to persons with dementia and their caregivers which is likely to impact on quality of life; however, these services do not meet the needs of all individuals; persons with dementia and their caregivers need paid in-home respite as an option; in some cases, having to bring someone to an ADP can have a detrimental impact on quality of life ▪ example provided in one area where this initiative has had a significant impact as it enabled the establishment of an integrated ADP for the South Asian community
#6: Research on Caregiver Needs	▪ as the reports have yet to be released, it is too early to determine impact
#7: Advance Care Planning	▪ as the data are still be analyzed, it is too early to determine impact
#8: PRCs	▪ some participants reported that there has been an increase in the use of the PRCs, and that the support and consultation they provide has been excellent; this has an indirect impact on quality of life ▪ others reported that the impact of the PRCs varies; where they are well coordinated with specialized geriatric psychiatry services, they are a very helpful resource (i.e., more education and support is provided to staff); where they are not well coordinated, there is less of an impact
#9A: Dementia Networks	▪ since the dementia networks are still in the early stages of development, it is too early to determine impact
Overall	▪ the Strategy is comprehensive and focuses on all aspects of dementia care (from pre-diagnosis to palliative care); all of the initiatives have the potential to impact on quality of life; if the funding is removed, many crucial initiatives will be halted ▪ there has been an impact with some initiatives; for others, we have to wait ▪ quality of life has been affected because the Strategy has enhanced the continuum of care (e.g., respite services, training for staff, introduction of the PRC role) ▪ while there has been an increase in service, it has not been enough to meet the needs (especially with the changing demographics); need flexible options to support families ▪ some respondents reported a difference in impact by sector, although the differences reported were inconsistent (i.e., some reported that there has been a greater impact in LTC facilities versus community and others reported the opposite)

1. Overall, how would you rate the success of the Alzheimer Strategy *to date* in terms of the following:

b) Improving the treatment, care and environmental conditions of persons with Alzheimer disease and related dementias?

Poor 1	Fair 2	Good 3	Very Good 4	Excellent 5	Mean (SD)
0	7.7% (1)	30.8% (4)	61.5% (8)	0	3.42 (0.66)

* Percentages may not sum to 100% because of missing values.
** Note: Frequency values have been rounded.

Summary of Comments:

There is a general sense that there has been a greater impact, thus far, on treatment and care versus the environment.

The following provides a summary of the responses, by initiative.

Initiative	Impact on Treatment, Care and Environmental Conditions of Persons with Alzheimer Disease and Related Dementias
#1: Staff Education	
▪ P.I.E.C.E.S.	▪ P.I.E.C.E.S. has been extremely successful; the drawback has been lack of funding to enable these individuals to undertake the role ▪ example provided of an area that has established a In-house PRP network to support these individuals (with assistance from the PRC)
▪ Support for Enhancing Care & Dementia Studies	▪ very successful in providing training – has had a direct impact on improving care ▪ EC has helped LTC facilities to look at environmental conditions; need to continue to provide funding for this in order to continue to improve design within facilities ▪ example provided of an Alzheimer Chapter encouraging facilities to include EC in their accreditation process
▪ P.I.E.C.E.S. & EC	▪ these initiatives helped to change the philosophy of one facility, which has had an impact on their care, treatment and environment
▪ Overall	▪ education of staff through Initiative #1 is key – it has increased: awareness and the implementation of useful approaches and interventions, and staff are more active in seeking help from partners
#2: Physician Training	▪ too early to know; initiative had a slow start ▪ family physicians are in need of education in this area
#3: PECs	▪ example of PECs reinforcing information from design conferences ▪ example of PEC coordinating sessions for various groups ▪ example of Alz Chapter providing suggestions to facilities re: environment

Initiative	Impact on Treatment, Care and Environmental Conditions of Persons with Alzheimer Disease and Related Dementias
#4: Appropriate Environments	▪ introduced staff to innovative and practical means of providing treatment and care ▪ conferences have helped to educate staff & volunteers; ▪ example of conference attendees now participating on local LTC redevelopment committees ▪ need funds in order to make changes to environment ▪ need to have those involved in care, and who are knowledgeable about the impact of the environment, involved in decision-making regarding design issues ▪ cannot forget about older facilities; need to help them identify what small/simple things can be done to improve environment ▪ distillation of information in terms of best practices, rigorous reviews of the literature, and the synthesis of materials in a way that they can be used, needs to be looked at ▪ as part of the conferences, there was no process to help facilities identify how they could look at design issues within their facilities
#5: Caregiver Respite	▪ needs of persons with dementia not met; need paid in-home respite
#8: PRCs	▪ example of PRCs being linked with In-house PRPs in order to enhance skills (and therefore, care and treatment) ▪ example of PRCs linking with specialists and assisting staff with educational issues between visits to the facility by the specialist ▪ PRCs provide an opportunity to coordinate meetings of the In-house PRPs to meet, network and upgrade their skills ▪ PRCs need to be linked and coordinated in order to be successful
#9A: Dementia Networks	▪ most impressive facet of the Strategy; enables individuals and organizations to work at all levels toward a common goal of care
Overall	▪ why has treatment and care improved? - front line staff in day programs and LTC facilities received baseline education and training on normal aging versus ADRD - many LTC facility staff, day program staff and volunteers attended the Dementia Studies courses offered at local community college - CCAC and LTC facility staff attended the P.I.E.C.E.S. training - physicians are targeted for education - opinion leader (physicians) across the province are being identified and supported ▪ in terms of treatment and care, significant investments have been made; things are happening that weren't happening before; more people are providing treatment and care which leads to improved access to services

Initiative	Impact on Treatment, Care and Environmental Conditions of Persons with Alzheimer Disease and Related Dementias
Overall (cont)	▪ the educational initiatives under the Alzheimer Strategy have done more than any other educational initiative in changing practice; improved knowledge and skills by providing a common language, common approach and common vision; focus on enhancing human resources and supporting organizational change ▪ there is inconsistency across the province – need time to see the potential benefits; need for continued support of these activities (e.g., through enablers) to ensure maximal benefits of the initiatives ▪ there has been an emphasis within the Strategy on making networks (e.g., P.I.E.C.E.S., PRCs, PECs) which is a good thing; however, the impact varies across the province – where there are links with resources in the community (e.g., specialized geriatric services), the situation has improved; where there are few (or no) such resources, the impact is limited ▪ there are numerous educational initiatives in the Ministry (e.g., stroke strategies, diabetes, palliative care etc); how can this knowledge be integrated so facilities see their connection to better care for residents as a whole person not as separate undertakings? ▪ one problem is the fact that there is still no movement on Initiative #9C (Review of Specialized Geriatric Services), so many areas of the province don't have adequate support (both geriatric psychiatry and geriatric medicine) ▪ It would be helpful to have geriatric medicine available to LTC in a more organized way, but funding and manpower are issues. Also need more Geriatric Psychiatry Outreach Teams to serve the population of all LTC facilities in the province. ▪ Specialized services need to work closely with family physicians to assist them in providing more treatment to those with dementia.

1. Overall, how would you rate the success of the Alzheimer Strategy *to date* in terms of the following:

c) Increasing public awareness of dementia and the services available?

Poor 1	Fair 2	Good 3	Very Good 4	Excellent 5	Mean (SD)
0	15.4% (2)	23.1% (3)	46.2% (6)	15.4% (2)	3.49 (0.92)

* Percentages may not sum to 100% because of missing values.
** Note: Frequency values have been rounded.

Summary of Comments:

Area	Increasing Public Awareness of Dementia and the Services Available
PEC impact on Public Awareness	▪ for some Chapters, huge increase in number of hours dedicated to public awareness ▪ reported increase in media coverage ▪ reported increase in requests for educational sessions ▪ reported increase in referrals to Chapters ▪ however, there is still a great deal of work to be done ▪ some variability in terms of the ability of the PECs to raise public awareness – some said that there were adequate resources to do so, others said that there were not, and that there may need to be a redistribution of resources
Impact from other parts of the Strategy	▪ public awareness of dementia has also been affected by other parts of the Strategy - the Advance Care Planning sessions that have been held for the public - the general awareness that others individuals/groups involved with the Strategy create (e.g., PRCs, dementia networks)
Overall	▪ Strategy has allowed for a stronger voice to be heard related to issues within LTC facilities and the community ▪ PEC positions have enabled Chapters to be involved in various educational initiatives, to provide intergenerational training, and develop a comprehensive library system ▪ Strategy has provided a constant reminder to the general public and those working with those with dementia that the disease is prevalent and that education and support is needed for both the client and the caregiver ▪ the Strategy should help to reduce the stigma associated with dementia; some said this has started to happen, others say the Strategy wasn't designed to do this ▪ more work needs to be done in this area; often, people wait to learn about something until they need to know about it ▪ Strategy has raised awareness among the public and providers ▪ need a multi-pronged approach to raise awareness – more than just the PECs; bigger impact when there are more involved in raising awareness

d) What benefits do you think will be realized over the next 3 to 5 years as a result of the Strategy in terms of:

The following provides a summary of the responses to this question. In addition, when asked about the benefits that will be realized over the next 3-5 years (parts i, ii and iii) some of the stakeholders spoke to the issue of *how* these benefits would be realized. These latter comments are summarized after Question 1d (iii).

i) Supporting and improving the quality of life of persons with dementia and their caregivers?

- greater educated awareness of dementia among family members
- we will start to see people accessing the right supports for their families
- higher levels of awareness among policy makers regarding the needs of persons with dementia and the importance of service providers working with these individuals
- decreased caregiver burden
- increased services / supports (e.g., adult day programs, support groups, counselling, education)
- increased self-advocacy among persons with dementia, leading to a better understanding of their needs
- less stigma
- greater comfort level approaching agencies like the Alzheimer Society for information and support

ii) Improving the treatment, care and environmental conditions of persons with Alzheimer disease and related dementias?

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

Care

- better trained staff
    - therefore, a better understanding of how to work with these clients and families
    - staff will be more responsive to the needs of clients and families
    - staff will be more comfortable providing care
    - staff will access resources
    - clients will be less frustrated moving through the system
- increased number of trained staff
    - more time spent thinking about dementia and how to improve services
- higher standards of care in facilities and agencies
- increased awareness of what services are available to assist those with dementia
- more appropriate and timely referrals of clients (and earlier referrals)
- better communication among service providers
- more knowledgeable families
- greater acceptance of advance care planning (ACP); ACP practised by more people
- need more development, services and education regarding the person with dementia at the later stages of the disease
- research needed into best practices for those with dementia, and in LTC

Treatment

- earlier diagnosis and treatment
- more knowledgeable physicians regarding dementia and the services available

Environment

- better environments for buildings and individual homes
- the opportunity to implement better environments in new LTC facilities was lost because the current LTC facility standards pre-date the Alzheimer Strategy
- LTC facilities are limited in terms of the environmental changes they can make because of the funding available

iii) Increasing public awareness of dementia and the services available?

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

- impact on public awareness varies across the province – depending on the PECs, PRCs and other resources
- public awareness about ADRD; this will lead to a better understanding of ADRD and more support for those with the disease and their family members
- better informed caregivers, care recipients, and care providers
- public awareness of the early signs of dementia
- public awareness of the needs of persons with dementia
- fundraising for ADRD may increase

- limited ability to support those from different ethnic backgrounds
- PECs more effective in targeting those with dementia and their family members versus the general public

How these benefits will be realized:

As mentioned above, in speaking about the benefits that will be realized in these areas in the next 3-5 years, some stakeholders spoke to *how* these benefits would be realized. These comments are summarized below.

- Training - better trained staff will result from:
    - P.I.E.C.E.S. (because of the quick, holistic assessment it provides; benefits will especially occur when P.I.E.C.E.S. becomes ingrained in a facility)
    - *U-First!* & Dementia Studies (especially for unregulated health care providers)
    - Enhancing Care

- Dementia Networks
    - will help to increase awareness about ADRD
    - the networks will deal with systemic issues
    - can help to improve access to services
    - can help to support staff from LTC facilities and community agencies

- PRCs
    - as a result of the education they provide, and through the connections they make

- Collaboration
  - sharing knowledge
  - communication between community partners
  - working together to improve care and treatment

- Support to Sustain Strategy Successes
  - the benefits realized (and the likelihood of having further benefits) are dependent on the availability of continued support and sustainability
  - need commitment from government for support of training:
    - for P.I.E.C.E.S. training, including formalizing the role of the In-House PRP (e.g., acknowledging and recognizing the role)
    - for Dementia Studies
    - for physicians (e.g., mentoring programs)
  - respite services
    - for new ADP spaces, not just spaces in existing programs
    - for early-stage dementia clients
    - for respite options (e.g., in-home respite, overnight respite)
  - dementia networks
    - seed funding for emerging networks
    - funding to support network activities (e.g., First Link Coordinators)
    - support to hold local/regional meetings
  - PECs and PRCs
    - increase number of PECs based on population, PRC availability and geography

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

The major strengths of the Alzheimer Strategy, as identified by the stakeholder groups, can be categorized into three areas: planning, implementation and outcomes. A summary of the responses in each of these areas follows.

Planning

- the government undertook a rationale, comprehensive planning process
- there were strong political leaders who backed the Strategy
- the comprehensiveness of the Strategy is key (i.e., including service, education and research)
    - it tackles one problem on a number of fronts
    - it is truly a strategy versus just service increases
- built on existing sectors and supports
- very focused and clear about its goals
- included groups from all over the province
- interdisciplinary nature of the Strategy – it has brought together players around the table who haven't been together before. Because we don't support the person with dementia on a silo basis, we need a shared approach

Implementation

- Ministry support
    - there have been good leaders within the Ministry that know how to get things done

- Specific initiatives
    - #1: P.I.E.C.E.S. education in LTC facilities where 60% or more of residents have dementia; provided in practical terms
    - #1 & #2: funding for education, particularly continuing education, is rare but very important
    - #5: increase in ADP spaces
    - #8: support for staff in LTC facilities and community agencies
    - #9A: bringing partners together to address gaps in the system; sometimes its been the first time that these groups have been around the same table

Outcomes

- increased awareness of ADRD among the public, service providers, and within government; it has raised the profile of ADRD

- we've begun to develop a baseline competency for care providers

- linkages / collaboration
    - the Strategy has brought groups together that haven't worked together before (e.g., in developing *U-First!*, in local dementia networks)
    - it has helped to improve collaboration between institutional and community-based programs
    - it has linked people, ideas and resources (e.g., Dementia Networks, PRCs, physician opinion leaders, specialized geriatric services)

- increased understanding of partners and the roles they play; this has enabled the groups to work together (i.e., it's provided some common ground and understanding)

- identified activities/approaches to education and service delivery that have application to other initiatives (e.g., Mental Health Reform)

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

The limitations of the Strategy, or areas requiring improvement, are summarized below.

Sustainability
- sustainability is particularly important because of the changing demographics; we don't want to lose ground
- we can't just pull the plug, we need to hand it off with a sense that we won't lose what we've gained
- there's a sense that we're running out of time – especially since some initiatives took longer to roll-out than others (e.g., #2, #9A)

Support for Sustaining Strategy Successes
- need more parts of the Strategy to have ongoing funding
- as a result of the Strategy, some expectations have been developed (especially on behalf of the Alzheimer Chapters) and it is becoming difficult to fulfil these expectations without further support
- some have advocated for continued support of specific initiatives (e.g., #1 – In-House PRP role, #3, #5, #9A)
- respondents indicated a need to reconsider how some resources were allocated
    - PRCs allocated by population, but the availability of other services should be taken into account (e.g., 1 PRC for a large northern area does not make sense)
    - PECs – 1 PEC for Toronto does not make sense

Training
- lack of training for community sector - *U-First!* is starting to address this
- accessibility is an issue
    - need more distance education opportunities
    - difficult for home support workers to access training because of lack of replacement staff

Linking Physicians
- the opinion leader initiative (#2) is a good start, but needs more development
- uncertain if physicians are aware of resources available (e.g., #8)

Timing of Initiatives
- if the PRCs had been rolled out when the P.I.E.C.E.S. training was, it would have strengthened the impact of P.I.E.C.E.S.
- if the PECs and PRCs had been rolled out at the same time, it would have helped to clarify roles

Other
- need flexible respite options (e.g., provide caregivers with a respite envelope and have them decide how to use it)
    - geography and availability of services are also issues
    - need more in-home paid respite
- clarity required regarding roles, competencies, responsibilities and accountabilities of specialized geriatric services, PRCs, In-House PRPs and PECs
- the hospital system has been completely left out of the educational initiatives; hospital and community are linked – hospital staff need to be educated
- #9B – Research Coalition has not got off the ground yet
- #10 – missed the opportunity to capitalize on the new requirement for secondary school students to complete 40 hours of volunteer work – this also could influence career choices
- need a comprehensive strategy for the frail/complex elderly vs. disease-specific strategies
- need to learn from others across the country

4. a) 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)?

Poor 1	Fair 2	Good 3	Very Good 4	Excellent 5	Mean (SD)
0	7.7% (1)	7.7% (1)	46.2% (6)	30.8% (4)	3.98 (0.99)

* Percentages may not sum to 100% because of missing values.
** Note: Frequency values have been rounded.

Summary of Comments:

The stakeholders agreed that there had been a great deal of collaboration among the various groups. They spoke to the impact of this collaboration as well as the factors that have contributed to it. The stakeholders' responses are summarized below.

Overall
- the linkages and collaborations that have occurred are one of the biggest successes of the Strategy
- linkages have occurred among all of the groups listed (i.e., service providers, educators, researchers, policy makers, agencies, organizations, advocacy groups, and/or networks)
- however, there is still room for improvement; as well, collaboration is better in some areas than others
- need to involve the person with dementia as well as the hospital sector

Impacts of Collaboration / Linkages
- individuals are working together and utilizing each others' strengths and areas of expertise
- has created new opportunities for partnerships
- partners have a better understanding of each other and their respective roles – a synergy has come out of this (i.e., the total is greater than the sum of its parts)

Factors Contributing to Collaboration / Linkages
- dementia networks – a good example of collaboration
    - some specific products & projects have resulted because of this collaboration (which have had an impact on providers)
    - new connections are happening between groups
- PRCs
    - because of their role of linking people together, and their role with the Dementia Networks
- P.I.E.C.E.S. – has provided a sense of unity, a common link; we have similar philosophies
- Advisory Committee
    - without the work of the Advisory Committee along with the Work Group Chairs, it would not have been possible to have the links and spin-offs
    - good working relationships have developed

Other Issues / Comments
- how do we sustain these links? Need to have an ongoing focus and structure to continue these collaborations (e.g., a project or group requiring wide participation)
- need to look at how to mesh the various types of networks that are out there in order to look at the system of care versus disease-specific issues

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?

Stakeholders identified a number of benefits that will be realized over the next 3 to 5 years as a result of these linkages / collaborations. However, many indicated that there was a caveat – that these benefits would be realized if there were mechanisms to maintain and continue to foster these collaborations. The responses provided by the stakeholders are summarized below.

Benefits:
- care and support of persons with dementia will continue to grow
- more knowledgeable staff
- implementation and / or enhancement of standards of care (i.e., norms of practice)
- there will be a better understanding of what services are available and what these services can provide
    - as a result, persons with dementia and their families will use services more
    - providers will be able to identify gaps in service and can advocate to address gaps
    - better use of resources (e.g., appropriate referrals; clients/families will receive the right service at the right tine)
- increased sharing of information
- increased access to services
- more consistency in the care that's provided
- better support of staff from LTC facilities and community agencies
- groups can work together toward common goals
- a collaborative environment may help attract new staff to an area
- there will be better links with mental health services

Many of the above benefits will ultimately lead to enhanced quality of life and decreased burden of illness among those with dementia and their family members.

Caveat:
In order for these collaborations to be maintained and continue to grow, mechanisms to do so need to be in place. These linkages and collaborations need to become part of usual practice.

Other Comments:
- sustaining the dementia networks will be essential for these benefits to occur
- is there collaboration with other strategies?

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

Poor 1	Fair 2	Good 3	Very Good 4	Excellent 5	Mean (SD)
7.7% (1)	7.7% (1)	23.1% (3)	61.5% (8)	0	3.34 (1.01)

* Percentages may not sum to 100% because of missing values.
** Note: Frequency values have been rounded.

Summary of Comments:

Impacts:

- increased awareness of ADRD
    - within organizations, sectors, the government
    - leads to greater acceptance and understanding
    - begins to address the stigma associated with the disease
    - however, increased awareness also raises expectations for service which has been difficult for some organizations to handle
- increased capacity to provide service and/or education (e.g., by Alzheimer Chapters through the PECs; within ADPs; by the PRCs)
- has increased the number of clients served
- has given some organizations a place at the table – enabling them to meet and learn about other organizations, as well as have others learn about them
- has encouraged some agencies to step back and look at this population and identify ways to serve them better
- has provided members with access to training, which they are thrilled about; available to all organizations regardless of corporate status, which is beneficial to clients
- has provided members with opportunities for networking which is very beneficial; it enables them to learn from others and bring this information back to their own facilities/agencies
- there is more communication among members

Drawbacks:

- has created more work with no or limited supports for sponsoring agencies of new resources (e.g., PRCs, PECs)
- unregulated health care providers have not been targeted enough as of yet (within the educational initiatives)

Impact of Specific Initiatives:

- #1: increased awareness of the need for, and availability of, dementia-specific education
    - there are variations in terms of the success of P.I.E.C.E.S., Dementia Studies and Enhancing Care
    - some P.I.E.C.E.S. trained staff have left facilities, or do not have dedicated time to serve in this role
    - for Dementia Studies there are the issues of cost and lack of incentives for staff
    - Enhancing Care is time consuming
- #2: some progress has been made, but need to target those physicians who aren't already enthusiastic about dementia care
    - physician shortages is a major issue
- #3: has increased awareness and information

Impact of Specific Initiatives (cont'd):

- #4: some are using the information learned at conferences
- #5: increased number of spaces and/or new sites, but more flexible respite options needed
- #6: more information is available on caregiver needs, but members of organizations (e.g., caregivers) are disappointed because changes have not been implemented (Note: at the time of the stakeholder interviews, the report on the results of Initiative #6 had not been submitted to the Ministry.)
- #7: education materials on ACP are available
  - however, some have questioned the credentials of the facilitators (some participants in education sessions expected the facilitators to have a legal background)
- #8: significant impact in many areas; challenges still exist in a few areas regarding role clarity with the PECs
  - some areas are also challenged because the PRCs have to cover a large area, with few or no other specialized resources available
- #9C: no action has taken place yet on the recommendations arising from this initiative – this is a drawback

6. Please feel free to make any other comments about the Alzheimer Strategy or its impact.

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

General Comments:
- The government should be commended for undertaking this strategy.
- We are in the earlier stages of development with the Strategy – we haven't seen the full impact yet. However, there have been a number of benefits and as the Strategy continues these will continue and increase in number.
- However, there was concern expressed by many stakeholders about what will happen after the Strategy ends. While not all gains will be lost, some will if there is no plan in place, and some types of supports in place.
- In some cases, we're relying on the commitment of individuals for things to happen. But this is not a stable situation; if these individuals move on, the activities they've been undertaking may not continue (e.g., In-House PRPs). We need to enshrine the expectations of various roles and provide supports in order for the good work to continue.
- No one wants to see all of the good work and strong relationships dwindle because the support and focus to move forward are not there.
- People from Ontario will directly benefit from the continuation of the Strategy's successes.
- For the amount of money, we've done a lot.
- We need a new plan for the next 5 years – especially because of the demographics. We need regular follow-ups to the Strategy (e.g., every 2-3 years) to ensure it doesn't lose ground.
- The demographics are not going away.
- The collaboration has been very beneficial. Having the right people involved is key – we have some very dedicated people that have moved this Strategy forward (on the Ministry side and from the various sectors).
- We need to look at best practices/best practice models and then move in these directions.
- The Strategy has been positive, but only addresses one aspect of the management of the frail/complex elderly.

Comments about Specific Initiatives:
- #1: P.I.E.C.E.S. has made some significant impacts. Need to enshrine the roles of the In-House PRPs (e.g., identify expectations)
- #2: more work needs to be done on education of physicians; need physician buy-in
  - LTC facility physicians more familiar with Strategy than non-LTC physicians
  - LTC physicians impressed with the education and support initiatives
- #1 & #2: educational initiatives need to continue in a focused way
- #5: it was good that the number of ADP spaces increased, but this does not meet all the needs for respite; some are unable to leave their homes, or do not have local programs available – therefore, need more respite options (e.g., paid in-home respite)
- #6: this initiative will have no impact if the advice is not implemented
- #7: some concerns expressed about the education provided; it is a challenging area
- #8: in some areas there are still problems regarding the role and mandate, and accountability
- #9A: dementia networks are only as strong as the individuals at the table; challenging because staff are overloaded
- #10: a one-time intergenerational initiative is tokenism

Systemic Issues:
- physician shortages
- recruitment and retention of service providers

APPENDIX – List of Stakeholders

The following is a list of key stakeholders for Phase I of this evaluation.

- Alzheimer Society of Ontario (ASO)
- Ontario Association for Non-Profit Homes and Services for Seniors (OANHSS)
- Ontario Long-Term Care Association (OLTCA)
- Murray Alzheimer Research and Education Program (MAREP)
- Ontario Community Support Association (OCSA)
- Ontario Association of Community Care Access Centres (OACCAC)
- Ontario Home Health Care Providers' Association (OHHCPA)
- Regional Geriatric Programs (RGPs) of Ontario
- Regional Geriatric Psychiatry Programs of Ontario
- Ontario Interdisciplinary Council for Aging and Health (OICAH)
- Canadian Coalition for Senior's Mental Health
- Caregiver Network Inc.
- Ontario College of Family Physicians (OCFP)
- LTC Program Consultants from the MOHLTC Regional Offices