

Roundtable on Future Planning  
For People Affected by  
Alzheimer Disease and Related Dementias

**An ADRD PLANNING  
FRAMEWORK**

1st Edition

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## TABLE OF CONTENTS

<b>I</b>	<b>EXECUTIVE SUMMARY .....</b>	<b>5</b>
<b>II</b>	<b>DEVELOPING A FRAMEWORK FOR PLANNING .....</b>	<b>6</b>
	Addressing the Reality of Living with ADRD .....	6
	The April 2004 Think Tank.....	6
	The Roundtable on Future Planning for People Affected by ADRD.....	6
	Developing the Framework .....	7
<b>III</b>	<b>PLANNING FRAMEWORK OVERVIEW DIAGRAM.....</b>	<b>9</b>
<b>IV</b>	<b>THE FRAMEWORK IN DETAIL .....</b>	<b>10</b>
	THE VISION.....	10
	GUIDING PRINCIPLES.....	10
	<i>A Relationship-Based Approach to Care .....</i>	<i>10</i>
	<i>Ethical Principle of "Do No Harm".....</i>	<i>11</i>
	<i>Citizenry Rights.....</i>	<i>11</i>
	<i>Respect for Diversity and Inclusiveness .....</i>	<i>12</i>
	<i>Fairness in Eligibility and Accessibility.....</i>	<i>13</i>
	<i>Accountability .....</i>	<i>13</i>
	LIFE COURSE OF ADRD .....	14
	PLANNING PILLARS .....	16
	<i>An Informed Society .....</i>	<i>17</i>
	<i>Enabling and Supportive Environments.....</i>	<i>18</i>
	<i>Personal, Social, and System Connectedness.....</i>	<i>19</i>
	ENABLING MECHANISMS.....	21
	<i>Government Policy, Support and Adequate Resource Allocation .....</i>	<i>21</i>
	<i>Legislated Processes and Legal Mandate .....</i>	<i>22</i>
	<i>Engagement of ADRD and Broader Communities in Planning.....</i>	<i>22</i>
	<i>Community-Based Partnerships Enabling Collective Wisdom .....</i>	<i>22</i>
	<i>Performance-Based Service Planning, Delivery, and Evaluation .....</i>	<i>22</i>
	OUTCOME .....	23
	CONCLUDING COMMENTS .....	23
<b>V</b>	<b>APPENDICES .....</b>	<b>25</b>
	Appendix A: ADRD - The Magnitude of the Challenge.....	26
	Appendix B: Roundtable Terms of Reference.....	28
	Appendix C: Roundtable Membership and Other Participants .....	31



## I EXECUTIVE SUMMARY

The implications to society of the growing number of persons who will be affected by Alzheimer Disease and related dementias (ADRD) cannot be overstated. By 2010 the number of cases of dementia in Ontario is estimated to increase by nearly 40% over current levels. Understanding the needs of those with ADRD and their families, and planning how best to address those needs, is critical if they are all to maintain a high quality of life. After the conclusion of Ontario's five-year Alzheimer Strategy in 2004, the Roundtable on Future Planning for People Affected by Alzheimer Disease and Related Dementias was convened to develop an integrated and broadly-based planning framework that would address the impact of ADRD on government programs, communities, and Ontario as a whole. The Roundtable recommends that the Provincial Government adopt this framework in all planning activities that affect Ontarians living with ADRD and their partners in care.

The framework encompasses:

- **A vision of Ontario** where all persons with ADRD and their partners in care can live meaningful lives across the progression of the illness through active personal and community engagement.
- **A set of guiding principles** that stresses:
  - A relationship-based approach;
  - The ethical principle of "Do No Harm";
  - Citizenry rights, including autonomy and self-determination, interdependence, full engagement in life, and respect and dignity;
  - Respect for diversity and inclusiveness;
  - Fairness in eligibility and accessibility; and
  - Accountability.
- **Three planning pillars:**
  - Promoting an informed society;
  - Creating enabling and supportive environments; and
  - Sustaining personal, social, and system connectedness.
- **Five enabling mechanisms:**
  - Government policy, support and adequate resource allocation;
  - Legislated processes and legal mandate;
  - Engagement of ADRD and broader communities in planning;
  - Community-based partnerships enabling collective wisdom; and
  - Performance-based service planning, delivery, and evaluation.

All of these mechanisms are required if we are to realize the desired outcome, which is the vision of Ontario as a society where all persons with ADRD and their partners in care can live meaningful lives across the progression of the illness through active personal and community engagement.

While this framework has specifically been developed to plan for persons with ADRD, it can also work with provincial frameworks for other disorders. When implemented, the framework will have a beneficial and multiplier effect for all disorders that have a chronic, complex and evolving course.

## **II DEVELOPING A FRAMEWORK FOR PLANNING**

### **Addressing the Reality of Living with ADRD**

The implications to society of the growing number of persons who will be affected by Alzheimer Disease and related dementias cannot be overstated. By 2010 the number of cases of dementia in Ontario is estimated to increase by nearly 40% over current levels (see Appendix A for information on the magnitude of ADRD in Canada and Ontario). Understanding the needs of persons with dementia and their families, and planning how best to address those needs, is critical to the maintenance of a high quality of life both for persons experiencing ADRD and for those supporting them in their care. Planning will ensure communities across Ontario are proactive in addressing such needs, and have the necessary resources, approaches and supports in place to ensure that persons with ADRD and their families continue to live meaningful and dignified lives.

### **The April 2004 Think Tank**

As Ontario's Strategy for Alzheimer Disease and Related Dementias came to a close, in 2004 the Ontario Seniors' Secretariat hosted a Think Tank on Planning for People with ADRD. It brought together seniors, partners in care, researchers, and service providers to explore how best to respond to the impact of ADRD. It provided an opportunity to gain the input of a wide range of stakeholders on how to address this issue. At this time participants identified a number of desirable qualities of a planning framework, including that it should consider ADRD in the context of healthy aging, adopt a holistic and cross-sectoral approach, include an integrated and comprehensive community support network, address safety and security issues, and ensure non-discriminatory policies towards people affected by ADRD.

### **The Roundtable on Future Planning for People Affected by ADRD**

The Alzheimer Strategy Transition Project (ASTP) was launched in September 2004 to further mature Alzheimer Strategy initiatives. One of the ASTP's activities is the Roundtable on Future Planning for People affected by Alzheimer Disease and Related Dementias.

The Roundtable's mandate was to develop an integrated framework for future planning to address the impact of ADRD on Ontario as a community. The framework is intended to respond to the needs of those living with ADRD and their families by facilitating collaborative approaches and initiatives that cut across different ministries (such as housing, transportation, education as well as health and social services). By identifying the sectors affected and the linkages between them, the framework is to support all service sectors when planning to address the growing needs of persons with ADRD and their partners in care within the context of healthy aging. A comprehensive and coordinated planning approach will reduce costs by minimizing duplications, increase effectiveness, and generate multiplier effects. (See Appendix B for more on the Roundtable's terms of reference.)

The composition of the Roundtable reflects Ontario's regional and cultural diversity as well as the different sectors affected. Membership is also cross-linked with the other two components of the ASTP, which are the Provincial Alzheimer Group and the Alzheimer Knowledge Exchange. Represented on the Roundtable are:

- persons living with ADRD and their partners in care;
- service providers;

- policy makers and planners;
- academics and researchers; and
- citizen groups.

For a list of members of the Roundtable, see Appendix C.

## Developing the Framework

The Roundtable undertook a number of activities in the course of developing the framework. It drew upon the work of the Alzheimer Strategy and the Think Tank. A survey of Roundtable participants identified priority issues pertaining to those living with ADRD, and those delivering services to them. Consulting other policy planning resources provided an overview of framework options available. Representatives from relevant government and community sectors were invited to share their expertise to allow the Roundtable to consider the potential impact policies in each sector might have on others. The goal has been to develop a planning tool that will inform government policy formulation, community planning, and service development.

A Roundtable Working Group comprising representatives from the Roundtable, ex-officio members, ASTP staff, and other stakeholders recruited from outside the Roundtable was charged with the task of creating a draft planning framework (for members of the Roundtable Working Group, see Appendix C). The “life course” experience of ADRD provided one dimension by which to organize the issues facing people affected by such illnesses. A broad range of planning resource material was also referenced, including:

- *Strategic Directions in Healthy Aging and Continuing Care in Alberta – ADRD*, prepared by the Alberta ADRD Working Task Group (2002).
- *Planning for Canada’s Aging Population – a Framework*, prepared by the Committee of Officials for Federal/Provincial/Territorial Ministers Responsible for Seniors (2005).
- *Gender-Based Analysis – A Guide for Policy Making*, prepared by Status of Women Canada (1996).
- *Seniors on the Margins: Seniors from Ethno-cultural Minorities*, produced by the National Advisory Council on Aging (2005).
- *Caregivers of Persons with Dementia: Roles, Experiences, Supports and Coping, A Literature Review*, produced by the Murray Alzheimer Research and Education Program, University of Waterloo (2004).
- *In Their Own Voices: Guiding Principles and Strategies for Change Identified by and for Caregivers in Ontario*, prepared by Bryan Smale and Sherry L. Dupuis, Murray Alzheimer Research and Education Program, University of Waterloo (2004).
- *Beyond ‘Person-Centred Care’: A New Vision for Gerontological Nursing*, by M.R. Nolan et al, published in the *International Journal of Older People Nursing in association with the Journal of Clinical Nursing*, 13 (3a): 45-53 (2004).

The resulting planning framework builds on the research and experience developed during the Alzheimer Strategy and encompasses:

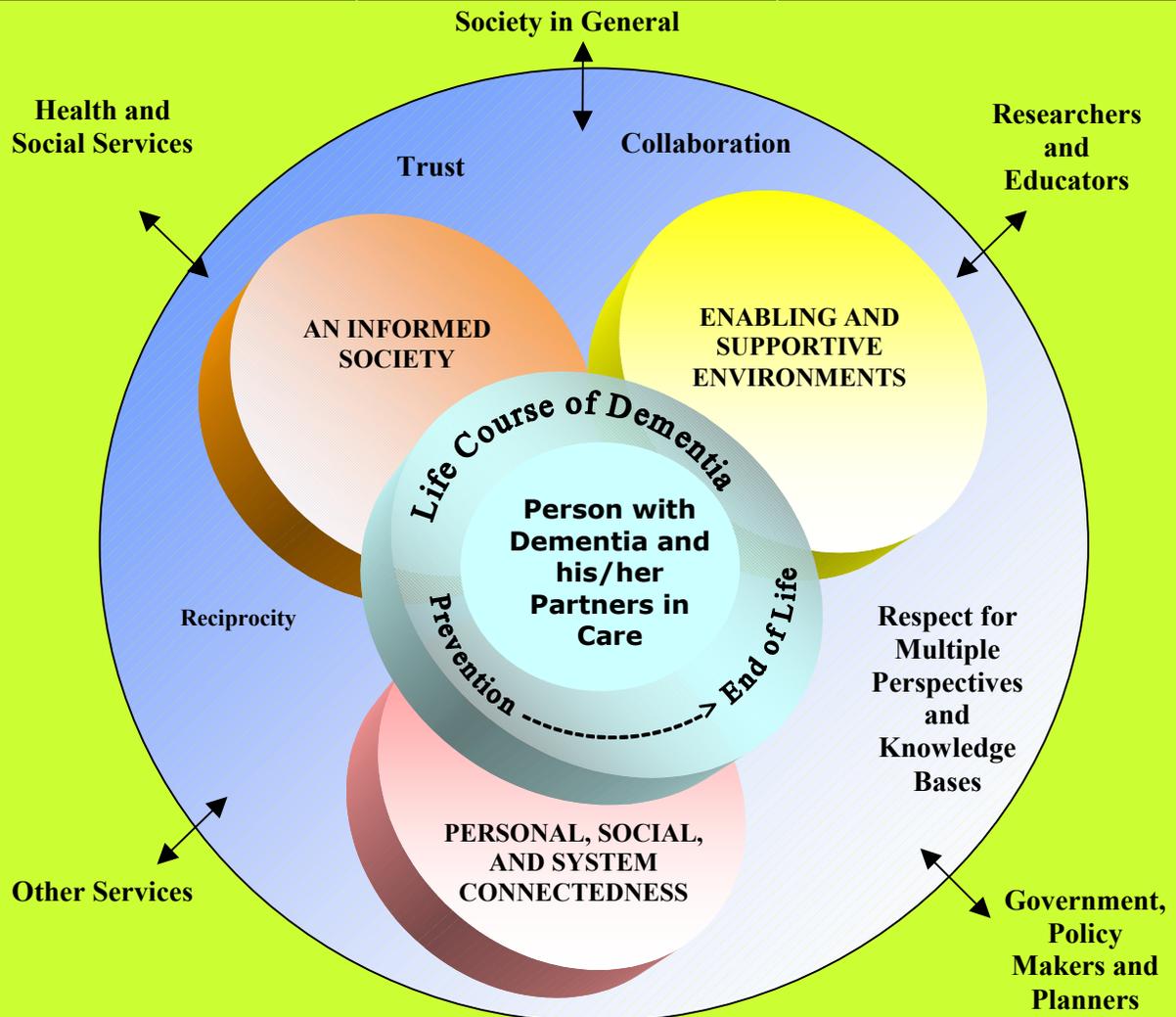
- a vision of Ontario in relation to persons living with ADRD;
- a set of guiding principles;
- three planning pillars; and
- five enabling mechanisms.

Accompanying the framework will be sector-specific toolkits that will guide planners, agencies, organizations, communities and individuals in implementing the values and principles inherent in the framework. The toolkits will translate the framework into more concrete terms by identifying specific actions that can be taken to put components of the framework into practice.

### III PLANNING FRAMEWORK OVERVIEW DIAGRAM

**Vision**  
**Ontario as a society where all persons with ADRD and their partners in care live meaningful lives across the progression of the illness through active personal and community engagement.**

- Guiding Principles**
- A Relationship-Based Approach
  - Ethical Principle of “Do No Harm”
  - Citizenry Rights
  - Respect for Diversity and Inclusiveness
  - Fairness in Eligibility and Accessibility
  - Accountability



- Enabling Mechanisms**
- Government Policy, Support and Adequate Resource Allocation
  - Legislated Processes and Legal Mandate
  - Engagement of ADRD and Broader Communities in Planning
  - Community-Based Partnerships Enabling Collective Wisdom
  - Performance-Based Service Planning, Delivery, and Evaluation

**Outcome**  
**Ontario as a society where all persons with ADRD and their partners in care live meaningful lives across the progression of the illness through active personal and community engagement.**

## IV THE FRAMEWORK IN DETAIL

### THE VISION

**The Vision**  
**Ontario as a society where all persons with ADRD and their partners in care live meaningful lives across the progression of the illness through active personal and community engagement.**

The planning framework aims at realizing a vision for Ontario as a society in which people living with ADRD and the family and/or friends who partner in their care are able to live meaningful lives in spite of the impact of their illness. It envisions that they are able to do so regardless of the particular stage of the illness in which they find themselves because Ontario, as a community, is able to approach their support in a thoughtful, sensitive and integrated manner.

### GUIDING PRINCIPLES

The recommended guiding principles, as shown in the table below, incorporate the values that provide the foundation for planning for people living with ADRD in Ontario.

**Guiding Principles**

- **A Relationship-Based Approach**
- **Ethical Principle of “Do No Harm”**
- **Citizenry Rights**
- **Respect for Diversity and Inclusiveness**
- **Fairness in Eligibility and Accessibility**
- **Accountability**

#### **A Relationship-Based Approach to Care**

While the well-being of the person living with ADRD is paramount, a focus on person-centered care alone does not fully capture the interdependencies that underpin the relationships between the person with ADRD and all those who assist in his or her care. Also, by focusing only on the person with ADRD or on the primary partner in care, one ignores the fact that the family, the community and society as a whole is affected by the illness experience. Further, placing the person at the heart of any plan for change can often result in systemic issues, such as environmental and social barriers to empowerment, being overlooked or undermined in favor of interventions targeted at the individual.

A relationship-based approach recognizes the connections between all those involved in dementia care. It acknowledges that care is affected by the dynamics and interactions of at least three parties:

- the person with ADRD;

- the informal helping systems (e.g., family partners in care); and
- the formal helping systems (e.g., paid care providers).

This approach encourages the development of meaningful relationships between people with ADRD, their family partners in care, and the formal helping system. It incorporates the broadest range of information and expertise available by valuing and respecting the diverse knowledge bases of all involved in dementia care. It recognizes that many disciplines contribute to delivering treatment and care and supporting and enabling those living with ADRD, and that the interactive process is built upon strong relationships between all partners.

It has been suggested that strong relationships in the provision of support and care are based on a sense of security, a sense of continuity, a sense of belonging, a sense of purpose, a sense of fulfillment, and a sense of significance experienced by all in the relationship—in other words, on an enabling and supportive environment.

In a relationship-based approach, the right, ability and availability of opportunities for any individual in the system (from the person with ADRD through family caregivers to the service providers) to relate to others in the system in a collaborative, cooperative, respectful, and reciprocal manner must guide all planning.

### **Ethical Principle of “Do No Harm”**

With the increasing number of Ontarians with ADRD, special attention should be given to the various ways in which they might be harmed. Neglect, undue restraint, inappropriate use of medications, and paternalism/maternalism (over-protectiveness) are some of the ways in which persons with ADRD might be harmed and suffer unnecessarily. There is a need for society to be informed about the potential for harm and to recognize the total vulnerability of persons with ADRD. At the same time the ethical principle of "do no harm" should be encoded at all levels in society to provide an environment in which people with ADRD can live safe and dignified lives.

### **Citizenry Rights**

The framework is guided by the recognition of a number of individual and community rights, including:

- ***Autonomy and Self-Determination***

The individual is acknowledged to have the right to live as she or he chooses and to remain as independent as possible (which includes recognizing the rights of individuals usually rejected by society, such as the gay, lesbian, bisexual and transgendered community). This requires strong collaborations (e.g., actively exchanging ideas, negotiating options, sharing power) between the person with ADRD, their partners in care, and health care professionals in the decision-making process. People with ADRD (and, when appropriate, their designated substitute decision-maker) have the right to make decisions about their care, to the extent possible over the course of the illness, consistent with their known values and cultural expectations. While a person with dementia is to be protected from seriously harmful consequences, it is equally necessary to respect his or her preferences and competent decisions. In keeping with a relationship-based approach, family members, health care professionals and staff at all levels should be included as a matter of course in decision-making and policy planning in a manner that supports the individual's wishes. Maintenance of autonomy and self-determination also requires access to all the relevant information that is needed to make informed choices.

- ***Interdependence***

Consistent with relationship-centered care, interdependence focuses on individuals, as members of the community, being dependent on each other, and on committed relationships of mutual support. It is often said that the depth and quality of human relationships determines the strength of society and the quality of lives, and that the building of strong relationships is the key to creating a better society. Recognizing the interconnections between personal, social and service-provider systems is a principle that must guide all planning.

- ***Full Engagement in Life***

At all stages of the illness, the individual has the right to be fully engaged in life. This acknowledges the continued potential of all persons with ADRD. Providing an environment that enables this engagement requires understanding the person's hopes, goals and aspirations, and assisting him or her to achieve them and to continue to grow and develop. It requires knowing what resources are available, and providing access to meaningful interactions and activities that support and enable the individual with ADRD to be as independent and self-directed as possible. It requires paying attention to and decreasing the triggers that create anxiety, and ensuring that all persons with ADRD continue to be engaged and connected with his or her community through participation and involvement.

- ***Respect and Dignity***

All approaches to care and caring relationships must acknowledge that all individuals, including those living with ADRD, are inherently valuable members of society. All persons, therefore, deserve to be treated with respect and esteem. Care providers should build their competency and ability to communicate with and support the person with ADRD in a manner that fully respects their rights. The maintenance of human dignity requires the elimination of humiliating practices and the stigma associated with dementia that cause unnecessary suffering to persons with ADRD and their families.

## **Respect for Diversity and Inclusiveness**

Diversity exists at many levels and settings:

- Ethno-cultural diversity in cities means that the recognition of and response to ADRD often manifests itself in different guises. Diverse and culturally-appropriate approaches to providing information/education are required to facilitate health promotion, detection, support, treatment, and care across the life course of ADRD.
- First Nations and francophone populations in parts of Ontario will reflect their unique traditions and community norms in the interface between family, community, and institutional responsibilities for care.
- The disparity between rural and urban populations demands different ways of allocating and deploying resources, as well as in facilitating access.
- Marginalized populations, such as the homeless or underhoused, face additional challenges when living with ADRD.
- Gender differences may be exaggerated within the context of ADRD, with men and women having different preferences and needs for support. Differences in life-span between men and women in general will also affect the availability of spouses/companions in later life.
- The continued momentum in Canada for same sex marriages and partnerships to become recognized with all the attendant legal rights will require structural

changes to meet their care needs as couples, both in the community and in long-term care homes.

- Although ADRD is primarily seen to be an illness associated with older adults, there are early onset variants of dementias where a “younger” population of people living with ADRD will have needs that are not routinely associated with an older adult population. Furthermore, the needs of persons with Down’s syndrome, who are at higher risk for subsequently developing Alzheimer Disease, and their often older partners in care, will be different and thus may require alternative approaches.

Each dimension of diversity needs to be recognized and considered with sensitivity in policy and planning decisions to avoid sweeping measures that precipitate inadvertent marginalization. This involves greater awareness and education at all levels of society including planners, service providers and the public, and an understanding of how to provide an individually-appropriate supportive environment. An inclusive approach to care embraces, and responds to, the diverse needs of all members of society. Individual attributes should not create barriers to care as a result of systemic inequities.

### **Fairness in Eligibility and Accessibility**

Those living with ADRD and their partners in care require formal health and social services across the progression of the illness. Ontario is geographically vast, and the cultural mosaic of its citizenry is complex and varied. Each of these factors can affect the access to resources. Supports, resources and services should be:

- based upon the real and changing needs, preferences and safety factors of persons with ADRD and their families, as determined by current personal information; and
- identified in collaboration and strong partnership with persons with ADRD and their family partners in care.

Eligibility and accessibility to supports and resources also should be guided by fairness. Diversity should not negatively affect a person’s eligibility for and accessibility to services and support. Ensuring everyone with ADRD lives in an environment that provides the supports they need means providing programs and services that are flexible enough to respond to the changing needs of persons with ADRD and their families, and that are equally accessible and available.

### **Accountability**

The overall goal of planning for ADRD is to optimize the quality of life for people living with ADRD and their partners in care.

This requires:

- a collective accountability by the people of Ontario to the vision expressed in this framework, including the use of performance indicators linked to the framework’s principles and values;
- accountability by the government to provide adequate resources and support to health care professionals, other service providers and partners in care, and to maximize the use of taxpayer dollars;
- accountability by health care professionals, other service providers and the broader community to use their skills and resources to the greatest effect for the benefit of those living with ADRD and their partners in care; and

- accountability of individuals and their families to participate, to the extent possible, in collaborative planning activities with service providers and the community.

At a more detailed level, this accountability includes:

- adhering to the principles outlined in the framework and being able to demonstrate adherence;
- clarifying the relationships between the different providers along the continuum of care and the responsibilities each carries;
- developing strong partnerships between all partners in care by identifying how all groups can work more effectively together;
- aligning resources and capacity with the responsibility;
- defining performance expectations and monitoring for results; and
- taking particular care with initiatives across different sectors where traditional accountability lines may be diffused.

Quite simply, it is important to be able to demonstrate that strategies and initiatives developed for persons with dementia and their partners in care make a positive difference in their lives.

## **LIFE COURSE OF ADRD**

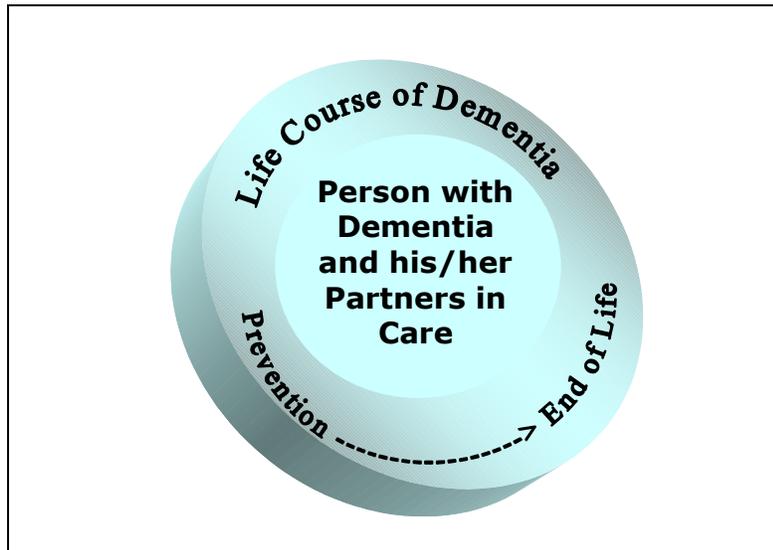
ADRD progresses in severity over time. This progression is often simplistically profiled in terms of early, middle, and late illness stages. In fact, many factors affect how the illness is experienced, including:

- Overall health status and make-up of the individual.
- Individual life-style choices. For example, current thinking in the medical sciences suggests stroke-related dementias account for a bigger proportion of the overall incidence of dementia than previously presumed. The risk of stroke in some situations is moderated by life style decisions.
- Interactions between the person and his or her environment.

In varying combinations, these factors influence:

- At the pre-diagnosis stage, what prevention activities are undertaken to modify life-style practices that may be correlated with risk factors for preventable dementias, such as vascular dementia, and the recognition of early symptoms suggestive of dementia (Mild Cognitive Impairment).
- In the early stages, how onset and the emergence of dementia symptoms are recognized and responded to, as well as how well the individual and partners in care sustain meaningful engagement in community living.
- Through the middle stages, how a changing need for support is met as the illness progresses, and how the person with an increasingly compromised cognitive capacity and their informal partners in care continue to remain engaged in interpersonal and societal participation while the strain of care increases.
- In the latter stages of dementia, how the illness manifests itself changes again with further declines and palliative care takes on added importance. Palliative and end-of-life dementia care encompass complex clinical, ethical and other

important considerations, which may occur in community-based and institutional palliative care settings.



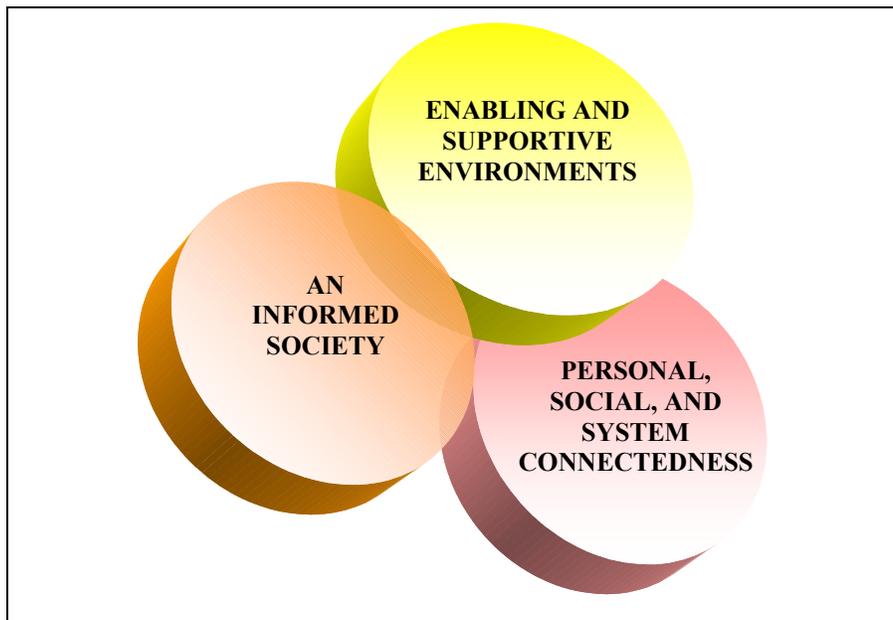
Given the different effects of these factors on each individual, sweeping assumptions about how ADRD progresses through discrete stages are of limited value. However, while individual experiences are unique, there are substantial shared experiences associated with different developmental points along the life course of these illnesses. It is imperative that all persons with ADRD, regardless of where they are in the life course of the illness, have opportunities to “live meaningful lives across the progression of the illness through active personal and community engagement.”

To provide a flexible system of care throughout the progression of the illness, it is suggested that three criteria — *an informed society, enabling and supportive environments, and personal, social, and system connectedness* — should be applied when formulating policies and service plans. Using these criteria as planning pillars at all levels in society will help determine systemic interventions across the life course of the illness, from prevention and early diagnosis through to the latter stages and end-of-life care, including support of partners in care after death.

## PLANNING PILLARS

The three planning pillars are grounded in the guiding principles of this framework. They encompass the essential life experiences that affect the well-being of the person seeking to live with the illness and those who partner with them in their care. These pillars are interdependent and are relevant at the individual, community, and systems levels. When used in planning, they address promoting and sustaining:

- an informed society;
- enabling and supportive environments; and
- personal, social, and system connectedness.



Each of the planning pillars incorporates a number of conditions that are necessary for the vision to be realized.

**Planning Pillars**

AN INFORMED SOCIETY	ENABLING AND SUPPORTIVE ENVIRONMENTS	PERSONAL, SOCIAL, AND SYSTEM CONNECTEDNESS
<ul style="list-style-type: none"> <li>• Individual and Public Awareness</li> <li>• Training for Service Providers</li> <li>• Learning Opportunities for the Broader Community</li> <li>• Discovery and Translation of Knowledge, and Use of Best Practice at All Levels</li> </ul>	<ul style="list-style-type: none"> <li>• Functional Physical Environment</li> <li>• Supportive Social Environment</li> <li>• Safety and Security</li> <li>• Flexible and Fluid, Need-based Access to Services and Support Across the Continuum of Care</li> <li>• Options in Self- and Facilitated- Care – Income Security and Support for Partners in Care</li> <li>• Equitable Approaches to Rural/Urban and Other Diversity Issues</li> </ul>	<ul style="list-style-type: none"> <li>• Continued Community Engagement and Participation</li> <li>• Consumer Input: Planning, Delivery, and Evaluation</li> <li>• Collaboration and Partnership among Service Providers</li> <li>• Linkages between Formal and Informal Support Sectors</li> </ul>

**An Informed Society**

An informed society is an important step in eliminating the stigma associated with dementia, and in assuring quality of care. The individual citizen is knowledgeable about his/her own health as well as about situations that affect others in the community. It requires ready access to the resources that support such a degree of awareness. An informed society in the context of dementia would be one in which all members of society had an informed and realistic understanding of ADRD. When ADRD-related information is effectively distributed at the individual, school, service, and broader community levels, then the preconditions for an informed society about ADRD are assured.

- ***Individual and Public Awareness: Reducing Risk, and Minimizing Stigma and Isolation***

The fundamental building block for public awareness is the individual’s right and access to information. This information incorporates the risk factors and life-style practices that may help reduce the risk of ADRD, how families can recognize the early symptoms, and how to live with the illness. It includes information about ADRD, and the services and resources that are available to support his/her efforts to address issues arising from the illness, as well as knowing which resources are unavailable. The more information persons with ADRD and their partners in care have about dementia, the more equipped they are to cope with the illness and plan for the future. Promoting to the public and to policy makers an awareness of, sensitivity to, and acceptance of the reality of ADRD, will in turn help reduce the isolation often experienced by those with dementia.

- ***Training for Service Providers***

All persons providing care to individuals with dementia and their families need specialized knowledge and training in dementia care. Included are physicians, other health care professionals and unregulated staff in community-based services, acute care settings, and long-term care homes. Also included are such ancillary services as the police, paramedics, fire services, and other emergency response agencies. A strong knowledge base about the progression, types and complexity of dementia and respectful care approaches is important to providing appropriate, good quality care. Education and training opportunities must be accessible to all such formal partners in care, and must be integrated into their usual practices. Opportunities for continued professional development are needed.

- ***Learning Opportunities for the Broader Community***

Since in the course of day-to-day living people with ADRD are not restricted to situations where they receive clinical treatment or care services specifically related to their health condition, awareness and understanding of ADRD must be fostered beyond the realm of the health and social services sector into the full spectrum of society, including but not limited to schools, financial institutions, legal services, public transit, retail and other service sectors. Employers should be made aware of the needs of employees who may have to leave the workplace for a while to provide care.

- ***Discovery and Translation of Knowledge, and Use of Best Practices at All Levels***

Accumulating knowledge on all aspects of ADRD remains an ongoing challenge. Only a modest amount of information on the cause, care and cure of ADRD is available though gains are slowly being made. Continued impetus must be given to supporting research efforts and propagating best practices in all settings. Ensuring research findings get to those who can use them requires a commitment to knowledge translation with strategies, programs and activities that focus on translating research findings in an accessible way into best practices. The return from such investment will be more cases of ADRD being diagnosed earlier in their onset which can delay the progression of the illness and enable better care planning, less crisis-precipitated use of high intensity services, more effective responses to the various impacts of ADRD, and ultimately a higher quality of life for all those experiencing dementia.

## **Enabling and Supportive Environments**

People with ADRD and their family partners in care are too often and too easily marginalized as they gradually lose friends, see important informal support systems shrink, and withdraw from participation in the wider community. Obstacles to community participation are preventable by, for example, having knowledgeable and skilled people in the community and providing local services and supports. Minimizing stigma and isolation of people with ADRD is of paramount importance.

- ***Functional Physical Environment***

Withdrawal from community involvement is often an inadvertent product of an inaccessible and non-accommodating environment. Appropriate homes and means of traveling are basic needs. Ensuring that one's residential needs are met, and that the means to reach services and socializing opportunities/facilities are available, is no less of a citizenry right for those with ADRD than anyone else in the community.

- **Supportive Social Environment**

Social isolation, stigmatization, and indifference compromise quality of living for both the individual struggling with the effects of ADRD and his/her partners in care. Measures are needed to support families getting on with life beyond just servicing the illness, for persons with ADRD to be involved in their communities, and to change society and community attitudes.

- **Safety and Security**

Both the community and the individual have the right to safe and secure environments. This requires care approaches and policies that protect individuals from exploitation or abuse. It also requires adequate income, and access to needed supports and resources from knowledgeable health and social service professionals. Safety and security concerns of the individual and the community should be addressed in planning with an emphasis on an inclusive approach to facilitating continued participation by those living with ADRD.

- **Flexible and Fluid, Need-Based Access to Services and Supports Across the Continuum of Care**

Enabling and supportive environments that allow families to live as normally as possible require services and supports that are flexible and based on the needs of individual families and not on administrative convenience. An example of this is thinking about and providing respite as an *experience* rather than a *program*.

- **Options in Self- and Facilitated-Care – Income Security and Support for All Partners in Care**

Some people living with ADRD remain capable and choose to manage their own care for as long as possible, whereas others more readily access structured assistance. Support for both options needs to be built into all planning initiatives. Family partners in care have stressed the importance of acknowledging and valuing the work that they do in providing care to relatives who are ill or have a disability living in the community. Critical to valuing the caregiving role is recognizing the financial strains of caregiving, providing adequate financial compensation for the work that family partners in care do in this regard, and developing options and specific policies to address the impact on the employment opportunities of family partners in care. Also important to valuing the work and expertise of families in the dementia context is to allow for those who would prefer to direct their own services to do so.

- **Equitable Approaches to Rural/Urban and Other Diversity Issues**

The challenges of living with ADRD are equally real and significant in rural and urban contexts, but they manifest themselves in different forms. The geographic dispersion of the rural population as opposed to the denser concentration of their urban counterparts will have differing implications for what constitute viable housing options, assistive transportation modes, and community support service designs. Planning to address such issues must be equitable in both rural and urban contexts as well as in other aspects of diversity without resorting to a “one size fits all” approach for meeting differing but comparable needs.

## **Personal, Social, and System Connectedness**

An individual, as a person, cannot be viewed in isolation. A relationship-based approach conceives of the person diagnosed with ADRD and his/her family partners in care as being actively connected with each other, with their community and with needed health care providers and professionals. The form and availability of health and social service resources (the “system”) relevant to helping persons with ADRD live meaningful lives

are inextricably connected through the community to the individual. Such connectedness dictates a deliberate planning approach that recognizes and facilitates meaningful relationships at the individual, community, and service levels.

- ***Continued Community Engagement and Participation***

Quality of life is connected to the opportunities available for individuals to actively and fully engage with her or his community. This means contributing to the shaping of those community activities and decisions as well as being affected by them. It is essential that persons with ADRD are not ignored or patronized because their cognitive capability is becoming compromised. They must continue to have meaningful opportunities to interact with the social environment over the life course of the ADRD experience. Opportunities for continued physical, cognitive, psychological, social, and spiritual health and well-being through engagement are critical and must be supported.

Just as the individual, in trying to adjust to the impacts of ADRD, is at risk of isolation from her or his surroundings, the family is also at risk of becoming detached from the community and important sources of support. It is equally important to encourage and support continued and positive engagement of families with their communities. Options for respite care and short-term admissions enable continued community engagement.

Over-reliance on admission to retirement homes or long-term care homes as the care arrangement of choice may perpetuate inadvertent isolation if not planned carefully and with full consideration for what is best for the individual with ADRD and their partners in care. Care must be taken to avoid unnecessarily restricting persons with ADRD and their partners in care from continued community participation, especially after a move to a long-term care home.

- ***Consumer Input in Planning, Delivery, and Evaluation***

The individual with ADRD and his or her partners in care, as consumers, are in a unique position to reflect on the efficacy and value of services and policies formulated to meet their needs. They must be seen as crucial partners actively involved alongside service providers in the planning, policy development, delivery and evaluation of programs and policies that are intended for their benefit.

- ***Collaboration and Partnership among Service Providers***

The needs of people living with ADRD are many and multi-faceted, and collaborations and partnerships are required to create an effective continuum of integrated care. Seeing their needs either exclusively in medico-health terms or purely in the realm of social care only minimizes the challenge. Doing so perpetuates an ineffectual band-aid approach to resolving a complex situation that affects and is affected by:

- medico-health challenges and opportunities;
- social care and support demands and opportunities;
- educational challenges and opportunities in promoting individual and public awareness;
- infrastructure gaps and opportunities in housing, transportation, and other service industries;
- financial impacts on the individual and his or her partners in care;
- economic costs and opportunities to businesses whose employees require flexible working alternatives or leave to take on the caring role full-time; and

- public policies in multiple realms of Ontario as a community.

No intervention in any one dimension can resolve the overall challenge of ensuring a reasonable quality of life for Ontarians living with ADRD and their families. Neither will any isolated intervention take place without generating ripple effects on the others. A relationship-based approach that proactively averts the silo effect and fosters collaborative planning is requisite for successful planning.

- ***Linkages between Formal and Informal Support Sectors***

Often, “informal support” such as that provided by family, friends, and volunteers is seen to be separate from “formal services” that are either delivered for pay, or funded by government and other public sector resources. Persons with ADRD and their partners in care have often had to choose between exhausting their own personal resources, funds and/or informal support before accessing community resources, or using formal services and relinquishing the ability to direct or control how such services are delivered to them. Instead, it is recommended that broad-based planning take into account a blending of formal and informal resources, and mandate processes for consumers to have input into how elements within the formal support sector are designed and delivered.

## ENABLING MECHANISMS

Five enabling mechanisms are required to support the implementation of the framework’s principles, values and planning pillars.

<u>Enabling Mechanisms</u>	
• <b>Government Policy, Support and Adequate Resource Allocation</b>	• <b>Community-Based Partnerships Enabling Collective Wisdom</b>
• <b>Legislated Processes and Legal Mandate</b>	• <b>Performance-Based Service Planning, Delivery, and Evaluation</b>
• <b>Engagement of ADRD and Broader Communities in Planning</b>	

### **Government Policy, Support and Adequate Resource Allocation**

The experience of Ontario’s Strategy for Alzheimer Disease and Related Dementias 1999-2004 demonstrated that the government’s leadership and support together with adequate funding and resources played a paramount role in ensuring the success of the Strategy. Ongoing service planning for ADRD that is sensitive to promoting flexible, need-based access to services and support across the continuum of care must also be assured of a proactive government policy of support and adequate resource allocation. This includes the government taking a leadership role in policy development, re-aligning resources (such as long-term care beds) to better meet demand where it is needed, developing blended funding options to allow for individual choices, and building the involvement of partners in care into strategic responses to ADRD.

## **Legislated Processes and Legal Mandate**

Respect for community leadership in addressing issues pertaining to ADRD enables the collective voice of people living with the illness and their partners in care to come to the forefront. Systemic changes—including but not limited to ensuring equitable approaches between urban/rural locations and sensitivity to other diversity issues—often require the authority of legal mandates. To anticipate and plan for enabling legislated processes will be integral to bringing about proposed systemic changes. These processes should incorporate a mechanism that ensures individual legal remedies.

## **Engagement of ADRD and Broader Communities in Planning**

In keeping with a relationship-based approach, it is essential that the community in general and the ADRD community of interest in particular be actively and meaningfully engaged in the planning process. Instead of the well-being of those living with such illnesses being planned for by others, they need to be included as full partners at the planning table. Garnering their input in generating ideas and feedback on proposals under consideration prior to their adoption and implementation is essential to arriving at plans that are responsive to the reality of their existence and respectful of their values. An inclusive approach in ensuring representation that reflects the diverse make-up of the community on all dimensions, and ensures that opportunities are made available for meaningful community participation in the planning process.

## **Community-Based Partnerships Enabling Collective Wisdom**

Specific demand for provisions to meet the needs of people living with ADRD varies with the local contexts. “Standardized” approaches to service planning often do not address such factors as the urban/rural dichotomy in service infrastructure, or ethno-cultural population mixes and their differing patterns of accessing services. Policy makers and planners are advised to reach for broad-based meaningful involvement of local stakeholders, as individuals or groups, and to leverage their collective wisdom and leadership. This will ensure that resource investments are made in ways that reflect local realities, and that the decisions reflect inclusiveness, ownership, local feasibility, and community buy-in.

## **Performance-Based Service Planning, Delivery, and Evaluation**

In accordance with the guiding principle of accountability, the intended outcomes and how they will be evaluated must be made explicit in any proposed plan to address the needs of the ADRD community of interest. Doing so will ensure that all involved accept responsibility and are accountable.

Responsible resource allocation requires articulation in any proposed business plan as to how the service is intended to be delivered, and the means of evaluation to be employed in demonstrating performance. The evaluation should include measurement of outcomes, including but not limited to satisfaction, perception of health status, and quality of life. Accountability is achieved not just through formal evaluation but also by informal feedback. Systematic structures need to be put in place to provide a continuous feedback loop by which intended beneficiaries of programs and policies can contribute meaningfully in their evaluation. Legal and administrative mandates should be specific in addressing all dimensions of planning, delivery, and evaluation. A clear demonstration to a strong commitment to the principles inherent in this planning framework is also needed in planning, delivery and evaluation plans.

## OUTCOME

The long-term, outcome of the framework will be the realization of the vision.

**Outcome**  
**Ontario as a society where all persons with ADRD and their partners in care live meaningful lives across the progression of the illness through active personal and community engagement.**

Operationally, outcomes from the application of this planning framework will:

- be specific to the public policy sector(s) involved in each planning initiative;
- demonstrate adherence by policy makers, planners, and service providers to these principles; and
- reflect conscious efforts by all stakeholders in ensuring coordination across sectors.

Successful outcomes must be measured in terms of how every planning initiative supports the quest to make Ontario an “informed society”, built of “enabling and supportive environments”, that supports “personal, social and system connectedness”. Reinforcing the objectives of these planning pillars throughout the planning, implementation and evaluation process is integral to fulfilling the framework’s vision of: ***Ontario as a society where all persons with Alzheimer Disease and related dementias and their partners in care can live meaningful lives across the progression of the illness through active personal and community engagement.***

The ultimate outcome will result in a high quality of life, increased satisfaction, and the opportunity to age well for persons living with ADRD and their families.

## CONCLUDING COMMENTS

This planning framework is intended to guide Ontario’s response to the needs of those affected by ADRD and their families and especially to facilitate collaborative approaches across sectors.

While planning frameworks are often intended for use by government departments and government-led planning bodies, this framework is intended for a wider range of end users. Policy makers and planners undertaking strategic planning in government ministries or local planning by regional authorities such as the Local Health Integration Networks (LHINs) and municipalities will find the framework of value in ensuring that any proposed policy and program initiative incorporates an integrated, comprehensive and consistent approach to issues of importance to the ADRD community of interest. The framework is equally useful for community organizations concerned with seniors, seniors’ health, and persons living with ADRD in ensuring that they take a strategic, global and integrated approach to service planning. Education and research organizations can also use the framework in developing their response to the information needs of persons with ADRD, their families and partners in care, service providers, and society as a whole.

The value of this framework lies in the comprehensiveness with which the proposed planning process is driven by:

- a clear vision;
- a coherent set of guiding principles;
- three encompassing and broad based planning pillars;
- five articulated and specific enabling mechanisms; and
- an outcome that is linked back to the vision powering the framework.

This framework has been developed with a focus on ADRD. However, many persons with ADRD may also have other concurrent disorders and the framework can complement and work with other provincial frameworks that address these disorders. It is also adaptable to other illnesses, particularly those with a chronic course. As a result, when implemented the framework will generate a multiplier effect in terms of effective methods, approaches, and result-based implementation strategies for all individuals with chronic illnesses.

## **V APPENDICES**

- Appendix A Alzheimer Disease and Related Dementias – The Magnitude of the Challenge**
- Appendix B Roundtable on Future Planning for People affected by Alzheimer Disease and Related Dementias – Terms of Reference**
- Appendix C Roundtable on Future Planning for People affected by Alzheimer Disease and Related Dementias – Membership and Other Participants**

## Appendix A: ADRD - The Magnitude of the Challenge

(Used here by permission of the authors – taken from Dupuis, S., Epp T., & Smale, B. (2004) *Caregivers of Persons with Dementia: Roles, Experiences, Supports and Coping, A Literature Review*, Murray Alzheimer Research and Education Program, University of Waterloo.)

According to the Canadian Study of Health and Aging (CSHA, 1994), one in thirteen Canadians over the age of 65 years is living with Alzheimer Disease or a related dementia. An estimated 364,000 older adults in Canada have an illness causing dementia (CSHA, 1994), of which over 64% have Alzheimer Disease, the leading cause of dementia (Johnson, Davis, & Bosanquet, 2000). Further, an estimated 83,200 new cases of dementia emerged in 2001 (CSHA, 2000) and the fastest increase in persons with dementia is occurring for those over 75 years of age (Gautrin, Froda, Tetreault, & Gauvreau, 1990). One in nine Canadians between the ages of 75 and 84 years is estimated to have an illness causing dementia and this statistic rises to one in three among those over the age of 85 years (CSHA, 1994).

With the rapidly increasing older adult population, the numbers of persons with dementia in Canada is projected to increase dramatically over the next several decades. The proportion of the Canadian population aged 65 years and older is predicted to increase from 11.4% in 1991 to an estimated 23.6% in 2031 (Public Health Agency of Canada, 2001). Consequently, the number of people with dementia in Canada is predicted to rise from 322,000 in 1997, to 548,000 by 2016 (Bland, 1998) and to 592,000 by 2021 (CSHA, 1994). By the year 2031, over three-quarters of a million Canadians are estimated to have Alzheimer Disease or a related dementia (CSHA, 1994).

Similar to national trends, the number of cases of dementia in Ontario is predicted to increase dramatically over the next two decades as the older adult population grows. By 2010, the number of cases of dementia is estimated to increase by nearly 40% over current levels and to increase by nearly 85% by 2020 (Hopkins & Hopkins, 2002). By 2028, the number of cases of dementia in Ontario will have grown by approximately 140% over 2000 levels (Hopkins & Hopkins, 2002).

These trends mean that approximately 181,306 people with dementia in Ontario will need some level of formal and/or informal care in 2010, rising to over 300,000 people needing care by 2028 (Hopkins & Hopkins, 2002). Nationally, the Canadian Study of Health and Aging Working Group estimated “that there will be approximately 60,150 new cases of dementia in Canada each year.” Of these, 36,320 will be women and 23,830 men (CSHA, 2000, p. 69). A sizable majority of these new cases of dementia will be persons living in the community (CSHA, 2000). The rapid increase in the number of people with dementia, and the efforts of the lay advocacy movement led by the Alzheimer’s Association in the United States and by the Alzheimer Society of Canada has led to the recognition of dementia as an international health priority, both for persons with dementia and for their families (Gillick, 1999).

**References:**

- Bland, R. (1998). Psychiatry and the burden of mental illness. *Canadian Journal of Psychiatry, 43*, 801-810.
- Canadian Study of Health and Aging. (1994). The Canadian Study of Health and Aging: Study methods and prevalence of dementia. *Canadian Medical Association Journal, 150*, 899-913.
- Canadian Study of Health and Aging. (2000). The incidence of dementia in Canada. *Neurology, 55*, 66-73.
- Gautrin, D., Froda, S., Tetreault, H., & Gauvreau, D. (1990). Canadian projections of cases suffering from Alzheimer's disease and dementia of Alzheimer type over the period 1986-2031. *Canadian Journal of Psychiatry, 35*, 162-165.
- Gillick, M. (1999). *Tangled minds: Understanding Alzheimer's disease and other dementias*. Toronto, ON: Plume, Penguin Group.
- Hopkins, R.W., & Hopkins, J.F. (2002). *Dementia projections for the counties, regional municipalities, and districts of Ontario*. (Geriatric Psychiatry Programme Clinical/Research Bulletin No. 13). Kingston, Ontario: PCCC Mental Health Services.
- Johnson, N., Davis, T., & Bosanquet, N. (2000). The epidemic of Alzheimer's disease: How can we manage the costs? *Pharmacoeconomics, 18*, 215-223.
- Public Health Agency of Canada. (2001). *Statistical Snapshots of Canada's Seniors: No. 1 - A growing population*. Retrieved August 29, 2006 from [http://www.hc-sc.gc.ca/seniors-aines/pubs/factoids/2001/no01\\_e.htm](http://www.hc-sc.gc.ca/seniors-aines/pubs/factoids/2001/no01_e.htm).

## Appendix B: Roundtable Terms of Reference

### A ROUNDTABLE ON FUTURE PLANNING FOR PEOPLE AFFECTED BY ALZHEIMER DISEASE AND RELATED DEMENTIAS IN ONTARIO

#### TERMS OF REFERENCE

##### Background

Ontario's five-year Alzheimer Strategy (1999-2004), through its ten initiatives, has garnered greater understanding of the needs of persons with Alzheimer Disease and related dementias (ADRD) and their caregivers. Some of these initiatives continue to receive funding support.

It is estimated that approximately 8% of Ontario's population over the age of 65 have ADRD. With the increasing number of seniors in an aging population, the number of people with ADRD in Ontario is projected to rise rapidly in the future and the supports required will become even greater. *What social and health system adaptations will be needed in the future to address the realities for people affected by ADRD in the context of an aging society, and to help people maintain a high quality of life for as long as possible?*

To address these questions and to ensure the sustainability of the successes of the Alzheimer Strategy, four inter-related yet distinct components have been proposed:

- Roundtable for Future Planning
- Provincial Alzheimer Group
- Alzheimer Knowledge Exchange
- Dementia Networks

The role and composition of a Roundtable was developed in a one-day think tank held in April 2004 entitled "Future Planning for Those Affected by Alzheimer Disease and Related Dementias". At an Alzheimer Strategy Invitational Workshop held later the same month, the Ontario Government announced its intention to form a new Roundtable on Future Planning for People Affected by Alzheimer Disease and Related Dementias. The Roundtable would be chaired by the Parliamentary Assistant to the Minister Responsible for Seniors and the Assistant Deputy Minister of the Ontario Seniors' Secretariat.

##### Purpose

The purpose of the Roundtable is to develop an integrated planning framework that will address the future impact of ADRD on government programs, communities, families and individuals.

The framework will incorporate the perspective of health and wellness. By identifying the range of factors that influence the quality of life of those affected by ADRD and their linkages across sectors, the framework will support those sectors in planning for persons with ADRD and their caregivers within the context of healthy aging. The framework, with its associated action steps, will serve as a planning tool to guide Ontario's response to a growing number of individuals affected with ADRD.

Through its broad membership 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.

### **Membership**

Membership of the Roundtable will be inclusive; it will reflect regional and cultural diversity as well as the different sectors that influence the broader determinants of health and well-being. These sectors include but are not limited to health, social services, housing, transportation and justice.

The membership will bring together the perspectives of:

- consumers and caregivers
- policy makers
- planners
- academics/researchers
- service providers

The Roundtable will have links with related initiatives such as the Provincial Alzheimer Group and the Ontario Inter-Disciplinary Council on Aging and Health.

### **Scope**

Whereas the Provincial Alzheimer Group will coordinate and oversee the systemic changes arising from the achievements of the Alzheimer Strategy and will retain the focus on improving service, the Roundtable will develop an overarching multi-sectoral planning framework to address the future impact of the rapidly growing population affected by ADRD.

### **Objectives**

1. To build on the opportunities and partnerships initiated through the Alzheimer Strategy by:
  - examining the role each sector may play in providing services to persons with ADRD and their caregivers and developing the inter-relationships between those sectors;
  - identifying the values, principles and philosophy of care underlying the provision of services and supports;
  - supporting a holistic approach to ADRD care and aging in Ontario that encompasses wellness and healthy aging; and
  - developing an integrated framework that will support the future planning of those sectors affected by ADRD and our aging society and promote the linkages between sectors.
2. To complement an Ontario Seniors Strategy, which will deal with the impacts of an aging population on Ontario society.
3. To inform and be informed by the work of the Provincial Alzheimer Group as part of a broad and complementary approach to planning for the future of Ontarians affected by ADRD, their families and caregivers.

## **Activities**

The Roundtable will plan its activities using a priority-setting and consensus-based approach. Ad hoc work groups may be created to carry out the tasks required.

It is recommended that the Roundtable:

- use the evaluation results of the Alzheimer Strategy as part of the development of a broad planning framework;
- extract knowledge from Alzheimer Strategy initiatives and other reforms that have broad implications for societal planning;
- identify best practices for learning, service delivery and research, and translate these into a planning framework; and
- draw on the expertise of Think Tank participants.

## **Deliverables**

The Roundtable will develop a high level planning framework that is integrated across sectors to address the societal impact of the rapidly growing population affected by ADRD.

The Roundtable will develop a plan to distribute and promote the adoption of the planning framework, including a process to disseminate interim findings. As part of a communication strategy, the Roundtable will take care in translating the framework and associated recommendations into language that is accessible to a wide audience.

The Roundtable will formulate a toolkit to support utilization of the recommended planning framework based on a set of policies and principles agreed to by the Roundtable membership.

The Roundtable will submit a report and recommendations to the Minister Responsible for Seniors. The report will include a time frame and action steps.

## **Accountability**

The Roundtable will be accountable to the Minister Responsible for Seniors through the Parliamentary Assistant. It will link to the Provincial Alzheimer Group.

## **Term**

Initially the Roundtable will have a maximum term of 22 months, from November 2004 to September 2006.

Roundtable members will be appointed initially for a term of 15 months, from November 2004 to March 2006, with the understanding that the term may be extended as a result of a review to September 2006 to allow for completion of mandated work.

## Appendix C: Roundtable Membership and Other Participants

### The Roundtable on Future Planning for People affected by Alzheimer Disease and Related Dementias

<b>Co-Chairs</b>	
<p><b>The Honourable Mario Sergio, MPP</b> (to March 2006)  <b>The Honourable Bob Delaney, MPP</b> (after March 2006)                      Parliamentary Assistant to the Minister Responsible for Seniors</p> <p><b>Mr. Geoff Quirt</b>                      Assistant Deputy Minister – Ontario Seniors’ Secretariat, Ministry of Citizenship and Immigration</p>	
<b>Members</b>	
<p>Dr. Brian Aitken (Laurentian University) *</p> <p>Det. Pat Blake (Hamilton Police)</p> <p>Mr. Alan Cimprich (Consumer) *</p> <p>Dr. Sherry Dupuis (MAREP) * ~</p> <p>Dr. John Feightner (University of Western Ont.)</p> <p>Dr. Luis Fornazzari (CAMH)</p> <p>Ms. Amy Go (Yee Hong Center for Geri. Care) *</p> <p>Dr. Michael Gordon (Baycrest Centre for Geri. Care)</p> <p>Mr. Al Gorlich (Consumer)</p> <p>Ms. Diane Harris (P.I.E.C.E.S. Canada)</p> <p>Dr. Ken Le Clair (PCCC – Kingston) *</p> <p>Dr. Parminder Raina (McMaster University)</p>	<p>Ms. Frances Maone (VAC)</p> <p>Ms. Lori Moran (University of Alberta)</p> <p>Ms. Judy Muzzi (United Senior Citizens of Ont.) *</p> <p>Ms. Sandra Pitters (City of Toronto)</p> <p>Dr. Dorothy Pringle (University of Toronto)</p> <p>Ms. Vania Sakelaris (MASA) <i>04/11 – 05/10</i></p> <p>Ms. Barbara Schulman (DN – Champlain)</p> <p>Ms. Linda Stebbins (ASO)</p> <p>Ms. Anne Stephens (St Michael’s Hospital) *</p> <p>Ms. Mary Sylver (Ont. Prevention Clearinghouse)</p> <p>Ms. Marilyn Truscott (Consumer)</p> <p>Ms. Judith Wahl (ACE) * ~</p>
<b>Ex-Officio Members</b>	<b>ASTP Staff</b>
<p>Mr. Michael Klejman (MOHLTC)</p> <p>Ms. Cheryl Szikita (MOHLTC)</p> <p>Ms. Elizabeth Esteves (MCI-OSS)</p> <p>Ms. Angie Szuch (MCI-OSS)</p> <p>Ms. Mercedes Zonan (PA’s Office to March 2006)</p> <p>Mr. Andrew Matheson (PA’s Office after March 2006)</p>	<p>Mr. Eric Hong, Project Manager (to March 2006)</p> <p>Mr. Scott Macpherson, Project Manager (from April 2006)</p> <p>Ms. Anne Anderson, Research Analyst</p> <p>Ms. Katherine MacDonald, AKE Coordinator</p> <p>Ms. Joan Honsberger, Project Officer</p> <p>Ms. Karen Parrage, Administrative Assistant</p>
<b>Guest Participants</b>	
<p>Ms. Marg Eisner (Alz. Society of Ottawa)</p> <p>Ms. Karen Henderson (Caregivers’ Ass. of Ont.)</p> <p>Ms. Salinda Horgan (PCCC – Kingston) * ~</p> <p>Ms. Frances Morton (MAREP, U of Waterloo) ~</p>	<p>Dr. Mark Oremus (McMaster University)</p> <p>Ms. Cecile Raymond (Toronto – CCAC)</p> <p>Ms. Susan Thorning (OCSA)</p>

- \* Member of the Framework Working Group
- ~ Member of the Toolkit Working Group